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ABSTRACT

An Indian child welfare agency realized the need for an HIV/AIDS policy when a diabetic child possibly exposed to the HIV virus was placed in one of the agency's licensed foster homes. A focus-group interview process was selected for policy development because this method appeared to parallel the Native American cultural approach toward consensus and decision making. Objectives of the project were: (1) to complete and present an HIV/AIDS policy draft to the board of directors and executive director; and (2) to document a positive change of 20 percent in the aggregate score for AIDS/HIV knowledge and attitudes among focus-group participants. Focus-group participants included agency employees, foster and adoptive parents, and other human-services representatives working with agency clients. All participants were either of Native American descent or working within the Native American community. Prior to the focus-group meetings, participants completed an HIV/AIDS knowledge and attitude questionnaire and received an information packet. After results of the focus-group meetings were compiled, comparative analysis of group recommendations and other available HIV/AIDS policies revealed that focus-group recommendations were similar to an existing policy that could be modified for the agency's purposes. Post-questionnaire results showed that the objective of a 20 percent improvement in scores was not attained. Appendices include the HIV/AIDS questionnaire, survey results, and other materials cited in the practicum report. (KS)

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The Drafting and Submission of an HIV/AIDS Policy Draft for a Native American Child Welfare Agency

by

Daniel "Pete" Holzemer

Cohort 52

Running Head: HIV/AIDS Policy

A Practicum Report Presented to the
Programs in Child Care, Youth Care, and Family Support
in Partial Fulfillment of the Requirements
for the Degree of Master of Science

NOVA UNIVERSITY

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AUTHORSHIP STATEMENT

I hereby testify that this paper and the work it reports are entirely my own. Where it has been necessary to draw from the work of others, published or unpublished, I have acknowledge such work in accordance with accepted scholarly and editorial practice. I give testimony freely, out of respect for the scholarship of other workers in the field and in the hope that my own work, presented here, will earn similar respect.

10-18-93
Date

Signature of Student

Abstract

The drafting and submission of an HIV/AIDS policy draft for a Native American child welfare agency. Holzemer, Daniel P., 1993: Practicum Report, Nova University, Master's Program for Child Care Administrators. Descriptors: Aids and Native American/ Indians of North American (Diseases)/Aids and Foster Care/Aids and Adoption/Aids in the Workplace/Aids Virus Carriers/HIV/AIDS policies/Aids (Disease) Government Policy.

The lack of any clear, comprehensive and functional HIV/AIDS policy for this Indian child welfare agency was a serious problem facing the agency's Board of Directors, administration, and staff. Documentation supporting the need for an HIV/AIDS policy was cited best where a diabetic child, possibly exposed to the HIV virus, was placed in the agency's licensed foster homes. Therefore, the foster parents were required to handle their foster child's blood when they administered insulin, using hypodermic needles.

The author selected and implemented the Focus Group process as the primary solution strategy to achieve the following Practicum goal: the drafting and submission of an HIV/AIDS policy draft for the management of cases in Indian child welfare. The Focus Group process was chosen because this method appeared to parallel the Native American cultural approach toward consensus and decision making.

The Focus Group participants were selected from agency employees, foster/adoptive parents, and other human service representatives working with agency clients. The commonality shared by all Focus Group participants was that they either be of Native American descent or working within the Native American community.

Four Focus Group sessions were facilitated by the author, with each group representing a particular geographic area. This strategy was employed to ensure proper demographic and cultural representation from this agency's Native American communities.

The Focus Group process as a solution strategy seemingly was as significant as the objectives it sought to achieve. The Focus Group participants felt as though their direct involvement was influential and highly recognized by the agency's hierarchial leadership. Clearly, the inclusive, participatory design of

the Focus Group process enhanced and encouraged ownership of and commitment to the submitted comprehensive HIV/AIDS policy so much so that the author strongly recommends that the Focus Group process be considered as a strategy for other agency policy development formats. Appendices include HIV/AIDS survey, survey results, and all other materials referenced in the Practicum report.

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CHAPTER 1: INTRODUCTION AND BACKGROUND

On April 17, 1979, this Indian child welfare agency was incorporated as a non-profit corporation. Its purpose and mission, as stated in the corporation document, are to prevent the unnecessary and unwarranted removal of Native American children from their biological parents and/or Indian environment.

It is the function of this agency to provide child and family services directed toward meeting the needs of clients. These services include, but are not limited to: (1.) professional counseling services to individuals, families and married couples seeking help for a wide variety of social service related issues; (2.) social service counseling and planning for single parents; (3.) adoption services; (4.) foster care; (5.) social service information and referral services; (6.) educational, cultural and family social service welfare consultation services to related communities; (7.) educational training services regarding the Indian Child Welfare Act and Indian child welfare concerns.

This Indian child welfare agency is tribally controlled through a Board of Directors whose

membership includes representatives from seven federally recognized Native American tribes and two additional members-at-large.

The organizational distribution of the agency staff is presently as follows: (1.) one Executive Director; (2.) two Casework Supervisors; (3.) twelve Caseworkers; (4.) one Business Manager/Accountant; (5.) two Case Aids; (6.) one Intake Clerk/Bookkeeper; and (7.) one Secretary.

Currently this agency has seven offices throughout the state, providing services to approximately one hundred Native American children and their families.

The position of the author with this Native American child welfare agency is that of the single Casework Supervisor, with an office located in the proximity of six of seven federally recognized tribes. The formal position job description reads as follows:

> Duties to include the training and supervision of Caseworkers and Case Aides. To ensure that assigned Caseworkers submit timely reports and other documents to comply with agency requirements. Provide final approval of family foster/adoptive home studies and placement into foster/adoptive homes. Provide direction

in family and individual counseling methods. Shall be responsible to act on behalf of the agency in securing needed services. Enforcement of agency policy in regard to placement and licensing of Native American homes.

Prior to the author's employment as an Indian child welfare Casework Supervisor, he spent twenty-five years in the juvenile justice system as a child care worker and a staff supervisor. At the time of his resignation, he was the Assistant Director of a one-hundred-bed, secure, juvenile residential detention facility. In addition, the author was for twelve years a licensed foster parent working with pre-delinquent and adjudicated delinquent teenagers. Through his professional career, he has served on and chaired numerous boards for local community, state, and national child care organizations.

CHAPTER 2: THE PROBLEM

The lack of any clear, comprehensive and functional HIV/AIDS policy for this agency was a serious problem facing the agency's Board of Directors, administration, and staff. Although the rate of reported AIDS cases among American Indians and Alaska Natives had been relatively low, AIDS surveillance and HIV sero-prevalence data clearly showed that HIV had entered the AI/AN population, with diagnosed AI/AN Aids cases increasing more rapidly than in any other racial/ethnic group. (Mather, Conway Stehr-Green, 1991) Due to the acceleration of the HIV/AIDS crisis among Native Americans, one would anticipate an increasing need for this agency to recognize the lack of behavioral and procedural HIV/AIDS policy as an increasingly serious and dangerous problem.

Documentation supporting the need for an HIV/AIDS policy with this Indian child welfare agency perhaps was cited best where a diabetic child, possibly exposed to the HIV virus, was placed in one of the agency's licensed foster homes. Therefore, the foster parents were required to handle their foster child's blood when they administered insulin, using hypodermic needles.

Further documentation had been obtained through

one-on-one interviews with health professionals working with Native Americans residing within this agency's service area. In an interview with the chief pathologist at the local community hospital, it was brought to the author's attention that there were, in fact, a number of substantiated HIV positive cases located on a nearby Native American reservation. (Chief Pathologist, personal interview, November 4, 1992) A recently interviewed tribal health care worker reported that an investigation was being conducted in regard to a known HIV positive female who has had sexual relations with numerous Native American males, perhaps as many as ten or more men living on area tribal land. These sexual encounters had occurred in spite of the female's awareness of her HIV infection. (Health Care Professional, personal interview, February 3, 1993)

In addition, a tribal HIV/AIDS counselor, in an interview with the author, had confirmed the presence of the HIV virus among the Native American populations served by this agency. (Tribal Counselor, personal interview, October 8, 1992) Clearly, the HIV/AIDS threat is not unique to Native Americans nor limited to Native Americans within the state served by this

agency. According to the American Indian/Alaska Native Tribal and Village HIV-1 Policy Guidelines (May, 1991) published by the National Native American AIDS Prevention Center (NNAAPC) in Oakland, California, communities, governments, programs and businesses all have important roles to play in reducing the transmission of the Human Immunodeficiency Virus (HIV-1) and must become more proactive in assisting those in need of service and support. The report further pointed out that this need exists not only for large urban centers, but equally as much for smaller and perhaps geographically isolated Native American reservations in rural communities and villages. (National Native American AIDS Prevention Center [NNAAPC]. May, 1991)

As of the end of September, 1992, the Centers for Disease Control, headquartered in Atlanta, reported 416 cases of AIDS among American Indian and Alaska Native Tribes. This most current figure represented an increase of 113 AIDS cases since the statistic of 305 AIDS cases among Native Americans reported in September, 1991. This reflected a 37% increase in confirmed AIDS cases within a one-year period. (American Indian Health Care Association. 1992)

These statistics alone did not begin to tell the real story. In an article published in the Detroit Free Press (January 12, 1993), Richard L. Vernaci of the Associated Press attempted to show that AIDS was having a greater impact on minority groups than on Whites. Reporting that as of September, 1992, there were 242,146 confirmed AIDS cases within a U.S. population of 250.6 million, he categorized these cases into reported racial groups. Among Whites, who comprise 76% of the total U.S. population, the report indicated that one finds 53% of all confirmed AIDS cases; 30% of these AIDS cases were found within the Black population, which comprises 12% of the U.S. population. Hispanics comprise 9% of the population, but 16% of AIDS victims. Asian Americans comprise 3% of the population and 0.6% of all reported AIDS cases. Native Americans, according to this report, comprise 0.8% of the U.S. population, but only 0.2% of the over 242,000 AIDS Cases. (Detroit Free Press. January 12, 1993)

Based on the above reported statistics, the author was tempted to perceive Native Americans as being a relatively low-risk segment of the U.S. population when considering the growing AIDS crisis. However, through

a continued literature search, additional data revealed that current statistics regarding this HIV/AIDS crisis among Native Americans must be challenged. A surveillance report from the Centers for Disease Control presented statistics for two major West coast cities, which certainly cast doubt on the assertion that the incidence of AIDS among Native Americans is limited to 0.2% of all U.S. AIDS cases as of September, 1992. (Centers for Disease Control. September 30, 1992) The surveillance report stated:

> In Los Angeles six out of eight American/Alaskan Native AIDS patients identified from case management programs were misreported to county health departments as White or Hispanic. Three out of four death certificates for American Indians/Alaska Natives with AIDS were reported as White. Four out of four death certificates for American Indians/Alaska Natives with AIDS reported them as White. (Centers for Disease Control. September 30, 1992)

Clearly, present statistics regarding AIDS among Native Americans are at best unreliable and at worst grossly erroneous.

The more optimistic statistics above become even more questionable when one examines the apparent high-risk behavior described in a report in Native AIDSBRIEFS, a newsletter of the American Indian Health Care Association. Using the Centers for Disease Control as its source, the report studied 416 cases of AIDS. Among this sampling, 55% of the cases involved men who have sex with men: 18% are or were IV drug users: and 14% are men who have sex with men and are also IV drug users. Only 2% are hemophiliacs; 4% are heterosexual; 2% contacted AIDS as a result of blood transfusions; and 5% of the cases remain undetermined. High-risk behavior among American Indians/Alaska Natives is a significant factor which cannot be overlooked. The extent to which this level of high-risk behavior differs from other racial and ethnic groups is not clear at this time. (AIHCA, Native AIDSBRIEFS Newsletter. Fall, 1992)

Initially, the author encountered considerable reticence among Native Americans to discuss HIV/AIDS policy. The subject appeared to be highly sensitive and a topic resisted by most Native Americans interviewed. This discomfort was thought to be the result of discussing a sensitive issue rarely a matter

of conversation among Native Americans. On the other hand, it may well have been that this issue touched upon an acceptance of and attitude toward divergent sexual behavior within the Native American culture which could be significantly different from the levels of acceptance and general attitudes one would find among other racial and ethnic groups. Walter L. Williams, in his recently revised book The Spirit and the Flesh, supports the idea that such a cultural difference does exist. (Williams, 1992)

CHAPTER 3: SOLUTION STRATEGY

Goals and Objectives

Goal 1: The draftingg and submission of a comprehensive and functional HIV/AIDS policy draft for the management of HIV/AIDS cases in Native American child welfare agency.

Goal 2: The enhancement of growth in knowledge and attitudes among Native American Focus Group participants regarding the HIV/AIDS issue among Native Americans and the need for appropriate policy.

Process Objectives

Process Objective 1: The collection of data, bibliographic searches, and one-on-one interviews with experts and clinicians in the HIV/AIDS arena.

Process Objective 2: The compilation of a preliminary HIV/AIDS pre-information packet for preparatory review and study by Focus Group members.

Process Objective 3: The consideration of additions, revisions and/or modifications to the pre-information packet in view of the critique.

Process Objective 4: The recruitment of Focus Group

participants and Reference Group participants.

Process Objective 5: The devising of a pre-post Focus Group survey questionnaire.

Process Objective 6: The completion and submission of the pre-Focus Group survey questionnaire prior to the Focus Group meetings.

Process Objective 7: The completion and submission of the post-survey questionnaire by all Focus Group members at the conclusion of Focus Group meetings.

Process Objective 8: The analysis of Focus Group data as a basis for drafting a preliminary HIV/AIDS policy.

Outcome Objectives

Outcome Objective 1: By the end of the 10 week Practicum, of the HIV/AIDS policy draft will be completed and presented to the Board of Directors and Executive Director for their consideration and deliberation.

Outcome Objective 2: At the conclusion of the Focus Groups, there will be evidence of a positive change of 20% in the aggregate score regarding knowledge and

attitudes among Focus Group participants; a final report will integrate the pre/post questionnaire survey and outcome reports, summarizing input, recommendations and consensus.

Strategy Employed

A critical review of the available professional literature and consultations with HIV/AIDS experts working with Native Americans resulted in the discovery of national and state Native American resource centers, proposed HIV/AIDS policy guidelines for tribes and villages, and numerous HIV/AIDS educational programs designed for Native Americans. However, the author's search did not reveal any policy or policy formats specifically designed for a Native American child welfare agency.

Based on the literature search, one-on-one interviews with HIV/AIDS experts, and reading on approaches to policy development, the type of solution strategy selected answered the following criteria:

(1.) that it be applicable to attaining the prescribed Practicum goals;.

(2.) that it provide a means to obtain pertinent information;

(3.) that it encourage participation and acceptance

by those served;

(4.) that it acknowledge and include the cultural and demographic characteristics of those served;

(5.) that it provide a means to measure identified outcomes;

(6.) that it be timely and cost-effective;

(7.) that it be an approach acceptable to the agency's Board of Directors and Executive Director.

The study and consideration of the above criteria resulted in the author's selection of a primary solution strategy: the facilitation of the Focus Group Interview Process. Morgan (1988) describes this process as the explicit use of the group interaction to produce data and insights not obtained easily through individual interviews or participant observation.

Ideally, a Focus Group should consist of no more than eight to twelve members building on each other's responses, thus uncovering information which would likely not result from one-on-one interviews. The recommended time frame for this small group interview process is one and a half to two hours. (Stewart &

Shamdasani, 1991) In their text, Focus Groups: Theory and Practice, Stewart and Shamdasani pointed out a number of advantages to the Focus Group interview process, which seemingly addressed the aforementioned criteria:

1. Focus Groups provide data from a group of people much more quickly and at less cost than would be the case if each individual were interviewed separately.
2. Focus Groups allow the researcher to interact directly with respondents.
3. The open response format of a Focus Group provides an opportunity to obtain large and rich amounts of data in the respondents' own words.
4. The synergistic effect of the group setting may result in the production of data or ideas that might not have been uncovered in individual interviews.
5. The results of a Focus Group are easy to understand. Researchers and decision makers can readily understand the verbal responses of most respondents. (pp. 19-20).

Finally, the Focus Group process was chosen by the

author because this method appeared to parallel the Native American cultural approach toward consensus and decision making. As Cleland (1992) explained, the principle of individual sovereignty in Anishinabeg political life meant that all group decisions were made as a matter of consensus. In other words, groups acted cooperatively, and leaders merely offered advice. This tradition is still much in evidence in today's modern tribal politics. Decisions are seldom made on the spot because tribal leaders feel the necessity to discuss matters with kin and friends "behind the scene." (Cleland, 1992)

An Ad Hoc Committee of Experts volunteered and was appointed to review and assess the initial policy draft, ensuring that it was realistic, concise, and factual. This professional committee also evaluated the draft and offered recommendations for revisions and additions, ensuring that the policy draft was comprehensive, functional, as well as legally, medically, and culturally appropriate. Members of this Ad Hoc Committee included a pathologist, a Native American AIDS support group counselor, a Native American AIDS counselor/therapist, a tribal judge, and a licensed state's attorney.

Report of the Action Taken

Employing the ten-week implementation calendar plan (Appendix A) presented in the Practicum proposal, the following discussion recounts in detail the action taken during the implementation phase of the Practicum project.

Week 1:

1. Present the Practicum proposal to the agency Board and Executive Director.

The author presented an overview of the Practicum project to the Board of Directors, incorporating the Practicum goals and the strategy for implementation. Included in this presentation was a brief summary regarding the literature search and personal interviews conducted to substantiate the need for a comprehensive HIV/AIDS agency policy.

While detailing the solution strategy to the Board, care was taken to assure them that policy input would be sought from all sectors of the agency's service area. They were informed that this would be accomplished through strategically located discussion groups, each representing a particular geographic and

demographic area.

Presenting the Practicum proposal to the agency's Board of Directors seemingly went well, taking approximately fifteen to twenty minutes. There were no questions asked regarding any of the materials presented. Although approval to proceed with the HIV/AIDS policy development process was obtained, the Board did request a progress report be given at the next scheduled agency Board of Director's meeting.

2. Recruit Focus Group participants.

For the purpose of the Practicum, the Focus Group participants were to be selected from agency employees, foster/adoptive parents, and other human service representatives working with agency clients. The commonality shared by all Focus Group participants was that they either be of Native American descent or working within the Native American community. Stewart and Shamdasani (1990) pointed out that the purpose of virtually all Focus Groups is to draw some conclusions about a particular population of interest, so the group must consist of representative members of the larger population. It was the intent of the author that the designed representation of the Focus Group participants

would not only provide valuable information, but also encourage acceptance of the HIV/AIDS policy through a sense of ownership.

This Indian child welfare agency's service area is statewide, thus dictating the recruitment of Focus Group participants representing particular geographic areas throughout the state. The strategy here was to ensure proper demographic and cultural representation from this state's Native American communities.

Initially, three Focus Groups were thought to be adequate to satisfy the above criteria. However, as contacts were being made within the Native American communities and with a number of Native American organizations, a high degree of interest in participating was expressed, so much so, that the addition of a fourth Focus Group was considered likely to be necessary to address the unexpected enthusiasm in developing a comprehensive HIV/AIDS policy for an Indian child welfare.

It was clear that the recruitment and facilitation of a fourth Focus Group would indeed create time constraint problems in light of the mandated ten-week implementation calendar plan. The factors and problems examined were as follows: (1.) the average number of

miles to be traveled per Focus Group would be approximately three hundred and fifty miles; (2.) all travel would occur during the winter months in a state known for its harsh winters; (3.) additional time would be required to orient a fourth contact person to the Practicum project and the Focus Group recruitment criteria; (4.) and additional time would be needed to compile, evaluate, and analyze additional data.

Following considerable discussion with both the student's Practicum Advisor and Practicum Verifier, it was decided that in order for this policy development process to be accurate and creditable and to encourage a sense of ownership among the agency's Native American constituents, adding a fourth Focus Group was indeed required.

The recruitment of the Focus Group participants was accomplished by assigning an agency employee working in each of the four designated areas as a contact person. These contact persons were mailed copies of the Practicum proposal, which included the following prescribed Focus Group criterion: That each participant be either an employed professional in Indian child welfare, or that he or she be a member of the Native American community. These agency employees

also assisted in the distribution of necessary Pre-Focus Group materials and arranged the time and location for the Focus Group meetings in their respective areas.

The recruitment of the Focus Group participants in each of the designated areas was completed within the first week of the Practicum calendar plan. All contact persons reported that they had no difficulty in finding willing and interested participants who met the required Focus Group criterion. The only difficulty encountered was that Focus Groups had to be downsized to the recommended eight to twelve participants in two of the designated areas.

Week 2:

1. Complete HIV/AIDS knowledge and attitude questionnaire.

The knowledge and attitude questionnaire was designed for this Practicum (Appendix B) from articles and reports obtained through a nationwide computer search, phone contacts and mailings from local, state and national HIV/AIDS prevention organizations, and information acquired through personal interviews with HIV/AIDS experts.

Contained in this HIV/AIDS questionnaire were twenty questions pertaining to attitude and twenty questions pertaining to knowledge. All of the questions were edited for accuracy and relevance by members of the previously identified committee of experts. Furthermore, the attitude and knowledge questions were mixed to avoid a "learning effect" by the Practicum participants.

2. Assemble the Focus Group pre-information packet.

Compiling the pre-information packet involved sifting through and reading all HIV/AIDS information obtained from the Practicum literature search. Special attention was given to conciseness and relevance, as well as to the assurance that the pre-information packet contained only information addressing the HIV/AIDS questionnaire and the topics to be covered in the Focus Group discussions. A preliminary reading of the materials selected was conducted by the author and several members of the Ad Hoc Committee of Experts. This reading involved approximately thirty minutes to complete.

Information in the Focus Group pre-information

packet included: basic facts concerning HIV/AIDS; statistics regarding Native Americans; suggestions concerning HIV prevention; and articles pertaining to legal, cultural, and social issues.

Week 3:

1. Arrange a time and place for the Focus Group meetings.

Coordinating a time and place for the Focus Group meetings was accomplished through the appointed agency contact persons. This process occurred on schedule without complications. Attention was given to the spacing of time between the Focus Group sessions, and to allow for the number of miles to be traveled by the author in order to facilitate each group. Weather was a factor only once, resulting in a three-week delay in scheduling one of the four Focus Groups.

2. Distribute HIV/AIDS knowledge and attitude questionnaire.

The HIV/AIDS knowledge and attitude questionnaire was distributed to all Focus Group participants either by their contact person or, where necessary, by mail. Accompanying the questionnaire was a two-page cover

letter (Appendix C) thanking the reader for his or her participation in the Focus Group process. Also included in this letter was a brief explanation of the author's role as the Focus Group moderator, a notice pertaining to the pre-information packet, and comments concerning the HIV/AIDS questionnaire.

Week 4:

1. Recruit participants for the Reference Group questionnaire.

The recruitment of the Reference Group participants was achieved through the efforts of a professional acquaintance who resides in another state and works within a heavily populated urban area. Following a brief orientation to the Practicum project, this contact person recruited thirty-four participants working in the human services arena.

When the selection of the Reference Group participants was completed, each was given the same Practicum questionnaire instrument, with attached instructions (Appendix D) that it be completed and returned to his or her contact person.

Because this Reference Group was comprised of professional individuals in human services selected

from an urban population in another state, it provided for the author a measure of presence or absence of any significant variances of different levels of knowledge and attitudes among the general population when compared with Native Americans. These comparisons are presented and discussed in the results section of this Practicum report. It should be noted, however, that the composition of the Reference Group was limited to an academic class of students of law enforcement. This fact was unknown to the author and likely skewed the results.

Week 5

1. Retrieve and score the Pre-Focus Group and Reference Group questionnaires.

The collection of both the Pre-Focus Group and Reference Group questionnaires was coordinated and accomplished by the contact persons. Collected were thirty-five Pre-Focus Group questionnaires and thirty-four Reference Group questionnaires. This process was timely and on schedule with the Practicum calendar plan.

The scoring of these questionnaires was aided by using an answer key sheet developed by the Practicum's

Verifier, who is an M.D. Pathologist and an HIV/AIDS expert.

2. Distribute the pre-information packet to Focus Group participants.

Upon receiving the Pre-Focus Group questionnaires each Focus Group participant was either given or mailed the previously described pre-information packet. All participants received packets for review within seven to ten days before their assigned Focus Group meeting dates.

3. Complete a Focus Group interview guide.

A proposed Focus Group interview guide (Appendix E) was prepared to serve as a guide for this moderator in leading the sessions. A fact sheet, Helpful Suggestions for Focus Group Moderators (Appendix F) (Wilhelm, 1986), was also utilized as an aid to facilitating the Focus Group sessions.

Week 6 through 10:

1. Facilitate the Focus Group process.

The author served as the moderator facilitating each of the four established Focus Groups. All four

sessions were audio recorded to ensure accuracy and enhance report writing. Once permission was obtained to audio record, an introduction and explanation of the role of a group facilitator was presented to each Focus Group. This clarification focused on the gathering and recording of Focus Group input and recommendations, while refraining from reactive judgments and comments regarding responses during the session.

Each Focus Group participant was then asked to introduce himself or herself to the group. These introductions were brief, including their names, where each group member was from, and an identification of any position or title held within or related to the agency, e.g., foster parents.

Upon completion of the introductions, a brief explanation of the Focus Group process was presented to the participants. They were advised that the process should be perceived as a collective group interview to ascertain their most consensual recommendations. Importantly, the participants were encouraged to understand that they were not being asked to make decisions, but rather offering recommendations to be seriously considered in a draft of an HIV/AIDS policy for the agency.

Initially, as discussed in the Practicum proposal, two different leadership styles were thought to be necessary to facilitate the four Focus Group sessions. That decision was based on the anticipated nature and frame of reference of the participants who would make up the various Focus Groups.

The style of leadership chosen and employed for Focus Group A and D reflected a low level of facilitator involvement. The rationale for this leadership strategy was that the participants in these two groups were primarily from rural areas, members of a particular tribe with a high level of group cohesion, and interpersonal familiarity.

With minimal moderator involvement, Focus Groups A and D participants proceeded to discuss the problems and their concerns related to the effect of HIV/AIDS on the Native American community. Furthermore, they presented points of view and recommendations as to what would be functionally relevant and culturally appropriate regarding the drafting and development of a comprehensive HIV/AIDS policy for Indian child welfare.

Using the newsprint approach, the moderator would occasionally write a word or a phrase which would summarize the discussion at hand while stimulating

further comments. The knowledge, interest, and group cohesion shown by these two Focus Groups was indeed striking. The low-level style of leadership involvement not only elicited the information sought for this Practicum project, but also seemingly encouraged a sense of ownership among the Focus Group participants regarding the HIV/AIDS policy development. Morgan (1988) thinks that a low-level style of leadership is beneficial even when there is an externally generated agenda, because it shows whether participants naturally organized their discussions around the same issues the researchers do.

It was assumed that Focus Groups B and C would need a considerably more direct, assertive leadership style. This assumption was based on the knowledge that these group participants, were residing within urban areas and without any direct tribal affiliation. Hence, they would probably lack the level of group cohesion and interpersonal familiarity in the first two groups. These participants were also expected to bring a far broader range of perspectives regarding the issue at hand because of their relative assimilation into the general population of their urban centers (Wax, 1977). Thus, a stronger leadership style was thought to be

necessary in order to keep the participants focused on the objective of the Focus Group sessions. Using the information gathered from Focus Groups A and D, the interview guide was more precisely followed, with facilitation carefully directed toward HIV/AIDS policy issues.

The moderator approach strategy for Focus Groups B and C proved to be quite inaccurate. Surprisingly, both groups required minimal leadership involvement. These two sessions were very similar to Focus Groups A and D regarding participant interest, group cohesion, and resultant recommendations offered for policy development. This occurrence seems to give credence to Vogt (1957) who argued that the acceptance of white material culture is often mistakenly equated with total acculturation. Just because Indians move to the city, live in modern houses, or watch color television does not guarantee that they give up important aspects of their culture, such as native religion, ties to the land, core values, kinship ties, or language (Vogt, 1957). Native American assimilation to urban life should not lead to the assumption that significant portions of their traditional culture are lost.

2. Evaluate and assess Focus Group input.

In order to evaluate each Focus Group session, adequately and promptly, an informal evaluative outline was completed by the Focus Group moderator as soon as possible after each Focus Group session (Appendix G). This particular evaluation outline, authored by Wilhelm (1986), was completed in a format and filed for later reference. It was essential to complete this task promptly while perceptions and reactions were still clear in the mind of the moderator. These notes assisted in planning future Focus Group sessions. They also proved to be valuable input for the aforementioned Ad Hoc Committee of Experts by providing specific recommendations for the submission of an HIV/AIDS policy for this Indian child welfare agency.

Concerning the pre/post questionnaire completed by the Focus Group participants, a qualitative measurement and evaluation were completed while taking into account the following measurable considerations:

1. an arithmetic average of scores and intra-group comparisons among the four Native American Focus Group participants as well as a measurement of any differences in levels of knowledge, or a lack thereof, among the

participants of the Reference Group.

2. an average of scores on the post-meeting questionnaire completed in a manner identical to the pre-meeting questionnaire survey the Reference Group did not complete the post questionnaire;
3. an average score and analysis of both pre- and post questionnaire responses to those statements related to attitudes, completed in the same manner as statements related to knowledge as outlined in Numbers 1 and 2 above;
4. an analysis to determine the percentage of change in the aggregate scores related to knowledge and attitudes of the HIV/AIDS issue among the Focus Group participants.

The data gathering and analysis component of this Practicum involved research from a number of available sources. First, a nation-wide data base search was conducted resulting in the identification of numerous articles and reports on HIV/AIDS and its effect on Native American populations. Secondly, through phone contacts and mailings to Native American Prevention Centers, the Centers for Disease Control and state

health organizations, the most current HIV/AIDS statistics and policy recommendations were procured.

Upon a thorough examination of the AIDS surveillance and HIV seroprevalance data, coupled with information obtained through interviews with Native American HIV/AIDS experts, clearly demonstrated that HIV had entered the AI/AN population.

Documentation supporting the need for an HIV/AIDS policy for this Indian child welfare agency was best cited by a specific case where a diabetic child, possibly exposed to the HIV virus, was placed in one of the agency's licensed foster homes. Therefore, the foster parents were required to handle their foster child's blood when they administered insulin, using hypodermic needles.

The evaluation of the information and recommendations received from the four Focus Groups was reviewed by the author and the Ad Hoc Committee of Experts for relevancy and accuracy. Also, the Focus Group policy recommendations were compared with the mandates of existing HIV/AIDS policy guidelines written specifically for American Indian and Native Alaskan tribes and villages.

Evaluating the results of the pre-meeting and post-

meeting HIV/AIDS knowledge and attitude survey questionnaire was accomplished through an arithmetic average of scores among the four Focus Group participants and the Reference Group participants concerning any differences of their levels of knowledge and attitude.

CHAPTER 4: RESULTS OF THE PRE/POST FOCUS GROUP HIV/AIDS SURVEY QUESTIONNAIRE

For the readers information, there were the following number of participants:

Reference Group 34

Total (all 4) Focus Groups-Pre- . . .35

Total (all 4) Focus Groups-Post . . .28

The following is a summary analysis of the survey to measure knowledge and attitudes regarding HIV/AIDS among four Native American Focus Groups and an ethnically mixed group in an urban center located in a different state. (A completed question-by-question scoring of the pre-meeting and post-meeting survey is located in Appendix H).

The results of the Native American Focus Groups and the summary statistics of all four Focus Groups indicate administration of the survey instrument prior to the receipt of an informational packet and the Focus Group session and the results of the same survey instrument administered at the completion of each Focus Group session. The survey included a random mix of twenty statements related to HIV/AIDS knowledge and

twenty statements related to attitudes concerning HIV/AIDS. Participants were asked to indicate their level of agreement or disagreement with each statement, or to indicate they did not know the accuracy of the statement (knowledge) or how they felt about the statement (attitude).

The Reference Group completed the survey instrument only once, and without the benefit of the informational packet or a Focus Group session.

Knowledge

	Correct Responses	Incorrect Responses	Don't Know
Focus Group A			
Pre	74.3%	11.4%	14.3%
Post	76.5%	11.2%	12.3%
Focus Group B			
Pre	80.7%	10.7%	08.6%
Post	70.0%	20.0%	10.0%
Focus Group C			
Pre	73.6%	09.6%	16.8%
Post	68.0%	18.5%	13.5%
Focus Group D			
Pre	79.3%	04.3%	16.4%
Post	78.0%	05.0%	17.0%
All Focus Groups			
Pre	***76.9%***	***09.0%***	***14.1%***
Post	***73.1%***	***13.7%***	***13.2%***
Reference Group			
Pre	66.5%	16.5%	17.0%

It should be pointed out that the Reference Group was comprised of a total number of participants essentially equal (within one) of the total of Native American participants in Focus Groups and proved to be significantly less knowledgeable. A comparison of the pre-surveys indicates a ***10.4%*** decrease difference among the Reference Group participants. A comparison of the Reference Group pre-test and the Focus Group post test, however, diminishes this difference to ***6.6%***. The Reference Group participants responded incorrectly ***7.5%*** more often in the pre-survey. ***When one compares the Reference Group pre-survey to the Focus Groups post-survey, there is a difference of 6.6%***. Percentages related to not knowing show no differences of 5% or more, and are therefore considered insignificant.

Results are also reported for combined Focus groups A and D, as well as combined Focus Groups B and C. Focus Groups A and D included Native Americans located in rural areas and at reservation sites. Focus Groups B and C are located in urban areas without reservations, and thus with populations of a more diverse ethnic mix.

	Correct Responses	Incorrect Responses	Don't Know
Focus Groups A and D			
Pre	77.0%	08.1%	15.4%
Post	77.2%	08.1%	14.7%
Focus Groups B and C			
Pre	77.2%	10.0%	12.7%
Post	69.2%	19.3%	11.5%

The rural Focus Groups remained remarkably consistent in their pre/post knowledge responses to the survey instrument. The two urban Focus Groups together shifted somewhat, but in the direction of incorrectness. These two groups show a 8% decrease in correct responses, and over a 9% increase in incorrect responses. "Don't Know" responses decreased by only slightly over 1%.

Attitudes

	Appropriate Responses	Inappropriate Responses	Don't Know
Focus Group A			
Pre	86.0%	04.9%	09.1%
Post	84.2%	08.3%	07.5%
Focus Group B			
Pre	80.0%	10.7%	09.3%
Post	78.6%	10.7%	10.2%
Focus Group C			
Pre	80.8%	09.6%	09.6%
Post	80.5%	08.5%	11.0%
Focus Group D			
Pre	96.4%	0%	03.6%
Post	90.8%	08.2%	01.0%
All Focus Groups			
Pre	***85.8%***	***06.3%***	***07.9%***
Post	***83.6%***	***08.9%***	***07.5%***
Reference Group			
Pre	73.6%	14.9%	11.5%

As with the report of HIV/AIDS knowledge, a report of combined rural, reservation Focus Groups A and D with a comparison to urban, non-reservation Focus Groups B and C.

Focus Groups A and D			
Pre	91.2%	02.5%	06.3%
Post	87.5%	08.3%	04.2%
Focus Groups B and C			
Pre	80.4%	10.2%	09.4%
Post	79.6%	09.6%	10.8%

Unlike the HIV/AIDS knowledge statements in the survey where there is no marked differences in results between rural and urban Focus Groups; statements about HIV/AIDS attitudes rural reservation Focus Group participants responded appropriately far more often than did urban non-reservation Focus Group participants. This difference may well reflect a more secure Native American culture which is inclined to display much more tolerance for inappropriate behavior.

An increase of ***10.8%*** of the rural participants indicated the appropriately accepted attitude as compared to the urban Native American participants in the pre-meeting survey. This difference is reduced to 7.9% in the post-meeting survey. Likewise, rural participants responded with inappropriate attitude responses only 2.5% of the time; while among urban Focus Groups the participants responded inappropriately 10.2% of the time -- a difference of 7.7% Interestingly, the post-meeting survey results show no significant difference (1.3%) between rural and urban Focus Groups. Among urban participants, 9.4% indicated they did not know their attitudes to the statements when completing the pre-meeting survey. Among rural

participants, only 6.3% did not know -- a difference of 3.3% In the post-meeting survey, however, 10.8% of the urban participants did not know their attitudes well enough to agree or disagree, while only 4.2% of rural participants did not know -- a difference of 6.6%

Unlike the results of the knowledge statements in the survey instrument, it was the urban rather than rural Focus Groups which remained remarkably consistent in their pre-meeting and post-meeting survey responses. The slight change (less than 1% in all cases) which the report includes is in an inappropriate direction. As in the shift from pre-meeting to post-meeting results among participants in the urban Focus Groups, the shift among rural Focus Groups was in an inappropriate direction, but somewhat greater. Appropriate responses decreased from 91.2% to 87.5% -- a 3.7% difference. Inappropriate responses in these same rural groups shifted from 2.5% to 8.3% -- a 5.8% difference. Percentages related to not knowing feelings about attitudes decreased from 6.3% to 4.2% -- a 2.1% difference.

It should be pointed out that the rural reservation Focus Group D remarkably exceeded all other Focus Groups in its selection of appropriate attitudes toward

HIV/AIDS. With an overall appropriate attitude response rating of 96.4% to the attitude statements, this group exceeded all other Focus Groups by as much 16.3% The Focus Group with the closest rating to its percentage is the other rural, reservation Focus Group A, with an appropriate rating of 86.0% -- a 10.4% difference. It should also be noted that the Focus Group D pre-meeting survey included no inappropriate responses, and only 3.6% participants indicated they did not know what their attitudes were.

This high appropriate percentage in the Focus Group D pre-meeting survey dropped to 90.8% in the post-meeting survey. Nonetheless this summary response still exceeded rural Focus Group A by 6.6% and Focus Groups B and C by 12.2% and 10.3% respectively.

COMPARATIVE ANALYSIS:

NATIVE AMERICAN FOCUS GROUPS/REFERENCE GROUPS

Finally, there is value in comparing the survey results of the Reference Group to the composite Focus Group results.

Regarding knowledge statements, a mere 66.5%, or two of every three Reference Group participants correctly responded to the pre-meeting survey. The remaining responses were rather evenly split between an incorrect response (16.5%) and a response of not knowing (17 0%). A comparison of the Reference Group pre-meeting knowledge survey to the composite Focus Group post-meeting survey is closer, but the Focus Group still exceed the Reference Group by 5.5%.

Reference Group participants responded with appropriate responses to the attitude statements at a rate of 73.6%. This compares to a composite Focus Group pre-survey result of ***85.8%*** and a post-survey result of ***83.6%***. This reflects a difference of ***12.2%*** and ***10.0%*** respectively. The Reference Group responded with inappropriate responses 14.9% of the time, compared to ***6.3%*** (pre) and ***8.9%*** (post) by all Focus Groups.

The following discussion is a comparative analysis of the Reference Group results (pre-meeting survey) and the composite of the pre-meeting survey of the four Focus Groups.

Knowledge:

Less than one of every two Reference Group participants disagreed with the faulty statement that an HIV-infected mother who does not breastfeed her infant cannot transmit the HIV infection to her child. Over four of every five Native American participants accurately disagreed with the statement in the pre-survey.

Slightly more than one of every ten Reference Groups participants disagreed with the erroneous statement that all auto-immune diseases involve a risk of developing AIDS. About four of ten Native Americans disagreed. It should be pointed out, however, that there seemed to be a significant lack of knowledge of the meaning of "autoimmune."

Less than seven of every ten Reference Group participants disagreed with the faulty statement that some nationalities and races are more likely by nature to be immune to HIV and AIDS. Nearly nine out of ten

Native Americans disagreed.

Less than half of the Reference Group participants disagreed with the erroneous statement that the HIV infection can be transmitted by handling soiled clothing. Six of ten Native Americans disagreed.

Slightly less than seven of ten Reference Group participants disagreed with the myth that the HIV infection can be contracted from public restroom toilet seats. Close to nine of ten Native Americans disagreed.

There were only two knowledge statements from among twenty where the Reference Group participants indicated any measurable increase of knowledge, compared to the Native American participants. Those include the following:

Somewhat less than six of ten Reference Group participants agreed with the accurate statement that an HIV-infected person must be presumed to be infectious even without the AIDS symptoms. Somewhat less than four of ten Native American participants agreed.

Seven of ten Reference Group participants disagreed accurately that wearing a condom during sex will assure a male that he will not become HIV infected. Less than six of every ten Native Americans disagreed.

Attitudes:

There was much more conflict among the attitudes of the Reference Group participants and the Native American participants. Two conclusions gleaned from the survey results appear to be reasonable.

For Reference Group participants, proximity seemed to be a major factor. So long as the attitude statement removed the respondent from any closeness or interaction with HIV-infected persons or AIDS victims, the response was inclined to be that which is normally and professionally acceptable.

Likewise, but with considerably less predominance, the Reference Group participants were far more likely than the Native American participants to reflect intolerance of socially unacceptable behavior which appeared to be considered by them as deviant. They also were far more inclined to respond to attitude statements out of a sense of personal moral judgments.

The most notable disparity between the attitudes of the Reference Group and the Native American participants related to an acceptable statement that HIV-infected and AIDS patients deserve to be treated with compassion and the best possible health care. While all Native Americans agreed with this statement, a

remarkably low 2.9% of the Reference Group participants agreed. In fact, 91.2% clearly disagreed.

Slightly over one half of the Reference Group participants disagreed with the unacceptable statement that HIV-infected employees should be prohibited from using restrooms available to other employees. Nearly nine of ten Native Americans disagreed.

Likewise, a similar number of Reference Group participants disagreed that HIV-infected individuals and AIDS patients should be isolated from others, an unacceptable attitude. Three of four Native Americans disagreed.

While 85% of Reference Group participants properly disagreed that anyone with HIV or AIDS can be assumed to have been involved in a deviant or otherwise socially or morally unacceptable life style, 96% of Native Americans disagreed.

Only 35% of Reference Group participants disagreed with the clearly unacceptable statement that wheelchair bound, frail persons, especially younger adults, most likely are HIV-positive or have AIDS. Over 96% of Native Americans disagreed.

To an unreasonable statement that a company or agency should refrain from hiring HIV-infected persons,

three of four Reference Group participants disagreed. Over 85% of Native Americans disagreed.

Only slightly more than one of four Reference Group participants disagreed with the unacceptable attitude statement that staff members found to be the HIV-positive should be promptly dismissed. Nine of ten Native Americans disagreed.

There were three attitude statements where survey results show a greater acceptable response among the Reference Group participants. Although inconsistent with other results, these responses included the following.

To the unacceptable, but not unheard, attitude statement that HIV-infection and AIDS are God's way of punishing individuals for immoral behavior; 68% of Reference Group participants disagreed, while only 36% of the Native Americans disagreed. The Native American response to the post-meeting survey climbed to 78% disagreement, however.

To the unacceptable attitude that a child should never be placed in an adoptive or foster home where a resident is known to be HIV positive, 53% of the Reference Group participants disagreed; but only 43% of Native Americans disagreed.

Over 91% of Reference Group participants disagreed with the unacceptable statement that HIV and AIDS are one more indication of the decay of family values. Seventy-five percent of the Native Americans disagreed.

In summary, it is clear that the Native American participants have more *KNOWLEDGE* of accurate facts about HIV infection and AIDS than does the Reference Group. More startling, however, is the marked increase in tolerance and acceptable *ATTITUDES* toward HIV infection and AIDS among Native American participants than is found within the Reference Group participants. A significant part of this result seems to reflect a general Native American tolerance for deviations from what these people hold as socially and culturally acceptable. This does not mean that Native Americans do not have strong convictions, but rather they are less prone to make judgments about the behavior of others. The survey results appear to bear this out.

The reader should note that there were a number of post-meeting survey statement results where the information packet and/or the Focus Group process resulted in movement (sometimes quite significant) to incorrect or inappropriate responses (See Appendix H). One of the stated objectives of this Practicum project

was to demonstrate a minimum 20% increase in knowledge and change in attitude concerning HIV/AIDS among the Focus Group participants. Not only was this not achieved, but the movement of attitudes reflecting the individual's reactions to increased knowledge was often in the markedly "undesirable" direction on the post-meeting survey results.

The author can only imagine one and/or two possibilities which may have caused this. First, the pre-meeting information packet included information which participants found frightening or alarming, thus precipitating a reactionary response in the incorrect or improper direction. Secondly, the intensity of the Focus Group discussions and/or the dominance of a particular vocal participant(s) might also have caused fright or alarm, thus slanting post-meeting responses.

A Comparative Analysis

Focus Group Recommendations/AI/AN HIV Policy Guidelines

A comparative analysis of the Focus Group recommendations to other available HIV/AIDS policies revealed that the Focus Group recommendations were accurate and relevant. In fact, the analysis resulted in the discovery of the American Indian/Alaska Native Tribal and Village HIV Policy Guidelines (May, 1991) published by the National Native American Aids Prevention center (NNAPC) in Oakland, California. The AI/AN HIV Policy Guideline Summaries (Appendix I) were carefully compared to the Focus Group topics and their recommendations. This comparison is illustrated in the following discussion:

I. Agency Responsibility

Focus Group Recommendations:

A. That a policy statement is in place acknowledging full access to services and employment for HIV persons who are otherwise qualified.

B. That the agency is sensitive to the HIV/AIDS crisis and is demonstrating this through client and staff HIV/AIDS policies coupled with an

ongoing training and education program.

C. That the agency's HIV/AIDS policies are geared to understanding the Native American Culture. Basically, a trust needs to be developed between agency staff and clients. The agency is obligated to provide trainings in the areas of cultural differences, communication techniques, values clarification and relationship building.

D. That the HIV/AIDS agency policy include a statement mandating staff to provide service without discrimination for clients at risk.

American Indian/Alaska Native Tribal and Village HIV-1 Policy Guidelines (May, 1991):

Legal rulings and regulations concerning descrimination and access to services in relation to HIV are discussed and explained (pp. 17-19).

II. Education

Focus Group Recommendations:

A. That the agency HIV/AIDS policy include an ongoing scheduled training component for the purpose of educating board members, administrators, employees, foster/adoptive parents,

and clients.

B. That the education/training format include, but not be limited to: basic facts and statistics to clear up any misconceptions, HIV transmission education, HIV testing, resource materials and speakers, especially those afflicted with the HIV virus.

American Indian/Alaska Native Tribal and Village HIV-1 Policy Guidelines (May, 1991):

Provides information on integrating HIV/AIDS education into existing agency programs, orientation formats, and philosophy. Also included in this section is a detailed discussion on critical facts regarding HIV and AIDS. (pp 20-30)

III. Universal Precautions

Focus Group Recommendations:

A. That the agency develop policies and procedures on infection control which are compatible with the work place and foster care settings.

B. That these infection control precautions are also congruent with other blood-borne pathogens, such as hepatitis A or B.

C. That the agency provide strategies regarding

what to do when an employee, a foster parent, a foster child, or anyone identified as having been exposed to HIV infected blood has been identified.

American Indian/Alaska Native Tribal and Village HIV-1 Policy Guidelines (May, 1991):

Provides a comprehensive approach to infection control protocols in relation to HIV, Hepatitis B, and other blood-borne pathogens (pp. 31-33).

IV. Confidentiality

Focus Group Recommendations:

A. That the "Need to Know" should be the specific criterion for HIV/AIDS disclosure.

B. That agency policy and procedures allow the disclosure of HIV information to foster parents and prospective adoptive parents with whom children are to be placed. This disclosure will assist the agency to recruit and retain placements for children and adolescents who may be HIV-infected or have AIDS.

C. That the policy and procedure standards provide strict disclosure steps for sharing confidential HIV-related information only to authorized

persons and for securing records that are stored in general or electronic files.

D. That strategies be employed to address self-disclosure by clients to others.

E. That the agency policy ensure that no one - employees, foster parents, or clients - be pressured to reveal his or her HIV status.

F. That a tribal attorney be consulted for the purpose of reviewing agency HIV/AIDS policies and procedures concerning confidentiality issues.

G. That State and local health authorities be consulted for current policies and rulings regarding confidentiality.

American Indian/Alaska Native Tribal and Village HIV-1 Policy Guidelines (May, 1991):

Provides information on HIV antibody testing and referrals. Also addresses issues such as who needs to know when a client self-reports HIV seropositivity, program responsibilities, and liabilities in relation to HIV status information, third party disclosure, charting protocols of HIV status, and other pertinent matters (pp. 34-49).

IV. **HIV/AIDS Specialized Foster Homes**

A. That the agency recruit and train foster parents for the purpose of establishing HIV/AIDS specialized foster family homes.

B. That the agency proffer an intensive needs reimbursement rate and supportive services to the HIV/AIDS specialized foster homes. Thus ensuring a good quality of life for as long as the child's health permits.

American Indian/Alaska Native Tribal and Village HIV-1 Policy Guidelines (May, 1991):

Specialized HIV/AIDS foster care was not addressed in AI/AN Policy guidelines. However, a continued literature search produced a similar program, established in 1985, at the Leake and Watts Children's Home located in New York City. Gurdan and Anderson (1987) conclude that this program has demonstrated that special foster parents can be recruited and foster homes established to serve children infected with the AIDS virus.

Continued research will be necessary concerning this particular Focus Group recommendation in order to ascertain this program's adaptability to this agency's

service related to foster homes and adoptive placements.

The enthusiasm and interest generated by the four Focus Group sessions was notable. Not only did the members in all the Focus Groups indicate a desire to know the results of their efforts and participation during the Focus Group meetings; many have reaffirmed to the author, often with expressions of impatience, their desire to learn more about how their input and recommendations are reflected in the results.

Clearly, there was a felt sense of fulfillment and inclusion among Focus Group participants. The opportunity to participate directly in a developmental process and influence decisions which will affect them and the agency was a matter of significant importance and pride. The implication of this result cannot be overlooked. The use of the Focus Group process resulted in an overwhelming perception of "ownership" in any ultimate HIV/AIDS agency policy. Of even more importance, however, corporate commitment to any policy will depend upon the extent to which the participants can see their recommendations reflected in the final product and the level of recognition and affirmation they receive for their efforts and time.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

The lack of any clear, comprehensive and functional HIV/AIDS policy for this agency was a serious problem facing the agency's Board of Directors, administration, and staff.

Documentation supporting the need for an HIV/AIDS policy with this Indian child welfare agency, perhaps, was cited best where a diabetic child, possibly exposed to the HIV virus, was placed in one of the agency's licensed foster homes. Therefore, the foster parents were required to handle their foster child's blood when administering insulin, using hypodermic needles.

Based on the literature search, one-on-one interviews with HIV/AIDS experts, and reading on approaches to policy development, the type of solution strategy selected was the facilitation of the Focus Group Interview process. The Focus Group process was chosen by the author because this method appeared to parallel the Native American cultural approach toward consensus and conclusion.

An Ad Hoc Committee of Experts volunteered and was appointed to review and assess the initial policy draft ensuring that it was realistic, concise, and factual. This professional committee also evaluated the draft

and offered recommendations for revisions and additions ensuring that the policy draft was comprehensive, functional, as well as legally, medically, and culturally appropriate.

The outcome objectives to be achieved by this Practicum were as follows:

1. The completion and presentation of the HIV/AIDS policy draft to the Board of Directors and Executive Director for their consideration and deliberation.
2. The evidence of a positive change of 20% in the aggregate score regarding knowledge and attitudes among Focus Group participants, a final report will integrate the pre/post questionnaire survey and outcome reports, summarizing input, recommendations, and consensus.

A careful comparison of the Focus Group recommendations to the mandates of the available American Indian/Alaska Native Tribal and Village HIV Policy Guidelines (1991) led the author to conclude that a draft of an original and new submission of HIV/AIDS policy statements not only unnecessary, but inappropriate. Focus Group discussions resulted in

suggestions and specific recommendations, all of which were essentially already included in the existing AI/AN HIV Policy Guidelines. To begin from base zero, ignoring the highly suitable policy which already exists, would serve no purpose beyond satisfying the ego needs of the author. So long as it met the needs and recommendations expressed by the four Focus Groups, it was the judgment of the author that it be adopted for submission to the Ad Hoc Committee of Experts and finally presented to the agency's Board of Directors.

An analysis and evaluation of the AI/AN HIV Policy Guidelines resulted in the conclusion that its adaptation to this Indian child welfare agency needs no more than appropriate revisions and/or additions to address better the agency's service related to foster homes and adoptive placements. Rather it would seem to call for an extrapolation of present policy statements to address this priority area of agency service more directly.

Regarding the Focus Group recommendation concerning HIV/AIDS specialized foster homes, Gurdin and Anderson (1987) offer the following suggestions:

1. Recruiting foster parents is a difficult task that requires a multi-faced strategy using both

formal and informal networks; media announcements generate a high volume of interest but the most appropriate candidates are located through foster parent and community networking.

2. Successful recruitment depends upon finding foster parents who are well informed concerning the disease, are not afraid of contagion, and, it would appear, have some medical background/ experience in caring for ill people.
3. Recruiting and keeping foster parents are made possible at our present level of knowledge about and treatment of AIDS by offering an exceptional boarding home reimbursement rate (even at this rate one month of foster care is less expensive than two days in the hospital) with continued financial assistance during hospitalization. Maintaining foster homes also requires intensive medical and psychological support services.
4. Because assisting foster parents and children places strong demands on staff members for support, information, and guidance, caseload size has to be small and staff members must

work as a team, with flexibility. (pp. 302-303).

Within the time constraints of this Practicum project to have completed an agency HIV/AIDS policy and the development of a specialized HIV/AIDS foster home program, the only result which could be reasonably accomplished was an outline for policy development, or in this situation an adaptation of an appropriate existing policy presented to the agency Board of Directors for their review and consideration of approval.

As has been stated, it was the objective of the Practicum project to demonstrate a minimum 20% increase in knowledge and change in attitude in what is considered by HIV/AIDS professionals as a desirable direction. Not only was this not achieved, but the movement of attitudes reflecting the individual's reactions to increased knowledge was often in markedly "undesirable" direction.

The Focus Group process seemed often to create an atmosphere of anxiety and fear as participants learned more about the frequency of HIV/AIDS among Native Americans, as they became better acquainted with the

casual manner in which the virus can be spread, and as they came to realize the serious risks which HIV/AIDS presents to all persons; the Focus Group dynamic seemed to create a high level of emotion and fear which was counterproductive to the Practicum objectives.

Another possibility causing the undesirable direction on the post-meeting survey results may have been the high level of group cohesion found in the four Focus Groups. Classic studies by Berkowitz (1954) and Schachter, Ellertson, McBride, and Gregory (1951) suggest that the more cohesive the group, the more power the members have and, therefore, the greater the influence members exert over each other. The sensitivity of the topic coupled with the intensity of the Focus Group discussions and the dominance of particular vocal participant(s) may also have caused fright or alarm, thus skewing post responses.

Although not completely unexpected, it was also clear that many Practicum participants had not prepared for their respective Focus Group meeting by reading the provided pre-information packet. Therefore, this author would highly recommend that any effort to adopt or replicate this project include a comprehensive educational program among Focus Group participants and

all other individuals, who will in any fashion, influence a resulting policy. Webman and Alwon (1990) point out that AIDS educators believe that people need to be exposed to AIDS-related information at least five times before they really understand it. Such a program should likely be three to six months in length, providing a comprehensive understanding (Knowledge) of HIV/AIDS upon which attitudes can be shaped and modified. Such an effort would accomplish the following:

1. better assure that Focus Group participants arrived at their respective Focus Group sessions with an assurance of accurate knowledge;
2. minimize group control by overly-vocal and extroverted group participants by the assurance of greater knowledge and confidence among other group members;
3. eliminate the initial anxiety and negative reactions which occur when an individual or group is faced with new and alarming information which can critically affect immediate attitudes in a negative and undesirable direction;

4. and assure essential, early support from the Board of Directors or other controlling leadership.

The possibility of mistrust among the Native American Focus Group participants toward outside leadership was a concern of the author. This was no small concern of this non-Native American author, who is a key staff person within a Native American child welfare agency, as well as facilitator/moderator of the Focus Group sessions. It was encouraging, therefore, to repeatedly be affirmed by Focus Group participants for the level of neutrality and sensitivity to Native American culture and mores reflected in the facilitation of the Focus Groups. While sensitivity, as well as neutrality, were deliberate efforts, further comments about neutrality seem appropriate. One of the learning experiences of the Focus Group process (as well as any other organizational process) was the simple fact that an outside facilitator is better able to maintain considerably more objectivity than one from within the group.

The Focus Group process was seemingly as significant as the objectives it sought to achieve. The Focus Group participants felt as though their direct

involvement was influentional and highly recognized by the agency's hierarchical leadership. This, having been accomplished, suggests that their affirmed involvement must not be minimized in any further HIV/AIDS policy development. The author strongly recommends that the Focus Group participants be reconvened at a later date to learn the results of their work. Even more, they should be provided with a facilitated process to react to and develop further recommendations for the HIV/AIDS policy.

The Focus Group process, as a solution strategy, was significant and impressive to all involved in this Practicum, so much so that the author recommends that this process be considered as a strategy for other future agency policy development formats. This particular strategy appears to coincide quite nicely with the Native American consensus approach toward decision making. Also, this inclusive participatory method benefits the policy development process by enhancing ownership and commitment.

The author has shared the Practicum and its results with representatives from this state's seven federally recognized Native American tribes, members of a local Aids Task Force Committee, this state's Foster Parent

Association, and of course, the aforementioned Ad Hoc Committee of Experts, comprised of professionals representing the medical, legal, and human service arenas located within this agency's statewide service area. Reactions to the Practicum results by the above-mentioned groups have been encouraging and positive. Much of the feedback centered around the author's rationale of the solution strategy employed, as a policy development process, for Indian child welfare. Further comment was obtained from a local Native American HIV/AIDS expert, who cited the Practicum for its "unique approach" toward HIV/AIDS awareness and education.

The Practicum goals and solution strategy were also shared and discussed with a national HIV/AIDS instructor employed by the Albert E. Trieshman Center, Needham, Massachusetts, known for its curriculum and training on HIV/AIDS related issues. As part of the author's dissemination plan, the final Practicum results will be submitted to the Albert E. Triechman Center, for review and comments.

Finally, while the approval and implementation of an HIV/AIDS policy was the objective of this effort, it is the conclusion of this author, that the most signif-

icant value of the Practicum project was the process, based on Focus Groups, used to develop a specific proposal for such a policy. The author will recommend to the agency's Board and Executive Director, that this Practicum's solution strategy, the focus group interviewww process, be considered and utilized as an integral policy development component, for this Indian child welfare agency.

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APPENDIX A

PRACTICUM CALENDAR PLAN

PROPOSAL PRACTICUM CALENDAR PLAN

Week 1:

1. Present the practicum proposal to the agency Board and Executive Director.
2. Recruit Focus Group participants.

Week 2:

1. Complete HIV/AIDS knowledge and attitude questionnaire.
2. Assemble Focus Group pre-information packet.

Week 3:

1. Arrange a time and place for the Focus Group meetings.
2. Distribute HIV/AIDS knowledge and attitude questionnaire to the Focus Group participants.

Week 4:

1. Recruit participants for Reference Group questionnaire.
2. Distribute HIV/AIDS questionnaire to Reference Group Participants.

Week 5:

1. Retrieve and score Focus Group and Reference Group questionnaires.

2. Distribute the pre-information packet to the Focus Group participants.
3. Complete a Focus Group interview guide.

Week 6:

1. Facilitate Focus Group A (Tribal).
2. Evaluate and assess Focus Group input.

Week 7:

1. Facilitate Focus Group B (Urban).
2. Evaluate and assess Focus Group input.

Week 8:

1. Evaluate and redesign the Focus Group interview guide to be employed for Focus Groups III and IV.

Week 9:

1. Facilitate Focus Group C (Urban).
2. Evaluate and assess Focus Group input.

Week 10:

1. Facilitate Focus Group D (Tribal).
2. Evaluate and assess Focus Group input.

The evaluation of the Practicum project will be based on an analysis of the Practicum goals and outcome objectives. Goal 1 and Outcome Objective 2 will be,

APPENDIX B

PRE/POST QUESTIONNAIRE

QUESTIONNAIRE

INSTRUCTIONS: After each statement circle the number which best reflects your personal opinion, using the following definitions:

5 = I VERY MUCH AGREE with this statement.
4 = I am inclined to AGREE with this statement.
3 = I am NOT SURE that or DON't KNOW if I agree with this statement.
2 = I am inclined to DISAGREE with this statement.
1 = I VERY MUCH DISAGREE with this statement.

1.	If an employee is HIV infected, the individual should be prohibited from using restrooms available to other employees.	5	4	3	2	1
2.	When caring for an HIV positive person where one is apt to come into contact with any body secretions, the care-giver should wear rubber (latex) gloves.	5	4	3	2	1
3.	HIV infected individuals or AIDS patients should be isolated from others without the virus or disease.	5	4	3	2	1
4.	If a new mother who is HIV infected does not breast-feed her infant, her infection cannot be transmitted to the child.	5	4	3	2	1
5.	Seeking better treatment of a cure for AIDS should be a national priority.	5	4	3	2	1
6.	HIV infection and AIDS are probably God's way of punishing individuals for immoral behavior.	5	4	3	2	1
7.	Persons infected with HIV must be presumed to be infectious even if they show no symptoms of AIDS.	5	4	3	2	1
8.	If an HIV-infected person ceases all high risk activity, such as unsafe sex and shared needle use, the person will not develop AIDS.	5	4	3	2	1
9.	If one has not been actively involved in homosexual activity, that person need not worry about being HIV positive.	5	4	3	2	1
10.	A child should never be placed in an adoptive or foster home where a resident is known to be HIV infected or have AIDS.	5	4	3	2	1
11.	Wiping a shared needle with a clean facial tissue will remove the risk of HIV infection.	5	4	3	2	1
12.	HIV infected persons and AIDS patients deserve to be treated with compassion and the best available health care.	5	4	3	2	1
13.	With all auto-immune diseases there is a risk of developing AIDS.	5	4	3	2	1

QUESTIONNAIRE

INSTRUCTIONS: After each statement circle the number which best reflects your personal opinion, using the following definitions:

5 = I VERY MUCH AGREE with this statement.
4 = I am inclined to AGREE with this statement.
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11. Wiping a shared needle with a clean facial tissue will remove the risk of HIV infection.	5	4	3	2	1
12. HIV infected persons and AIDS patients deserve to be treated with compassion and the best available health care.	5	4	3	2	1
13. With all auto-immune diseases there is a risk of developing AIDS.	5	4	3	2	1

31. Wearing a condom during sex will assure a male that he will not become HIV infected.	5	4	3	2	1
32. Because or the HIV risk, one should refuse blood transfusions, regardless of the medical source.	5	4	3	2	1
33. Persons who are HIV infected or have AIDS have only themselves to blame.	5	4	3	2	1
34. Because of the HIV risk, people should be discouraged from donating blood.	5	4	3	2	1
35. Anyone who is HIV positive can be certain of having AIDS sooner or later.	5	4	3	2	1
36. If a staff member is found to be HIV infected, the employee should be promptly dismissed.	5	4	3	2	1
37. HIV infection and AIDS are the result of homosexual activity and therefore should not be a high medical priority.	5	4	3	2	1
38. Hospitals should be free to refuse treating HIV symptoms and AIDS to protect other patients.	5	4	3	2	1
39. So long as an HIV-infected person takes safety precautions, he or she need not assume any responsibility to inform a sexual partner of his or her infection.	5	4	3	2	1
40. Our society should do all possible to engage the active participation and inclusion of HIV infected persons, taking only those precautions which are necessary and appropriate.	5	4	3	2	1

APPENDIX C

LETTER OF INTRODUCTION

February 21, 1993

Dear Focus Group Participant,

On behalf of the Michigan Indian Child Welfare Agency, I would like to take this opportunity to thank you for your willingness to partake in our Focus Group process. Your role as a participant is a primary component in the achievement of two important selected agency goals. They are:

> **Goal I:** The development of a comprehensive and functional HIV/AIDS policy for the management of HIV/AIDS cases among Native Americans.
>
> **Goal II:** The enhancement of growth in knowledge and attitudes among Native American Focus Group participants regarding the HIV/AIDS issue among Native Americans and the need for appropriate policy.

For your clarity and understanding allow me to briefly define and explain the Focus Group process. Basically, a Focus Group is comprised of eight to twelve participants of varied backgrounds coming together to discuss and provide valuable input on a particular topic(s) and related issues. Here, I need to point out a commonality shared by you and your fellow Focus Group participants. All of you are either members of, or directly working with the Native American community. As a member of this group, you will have the opportunity to provide your knowledge, concerns, insights, and opinions as we work toward the aforementioned goals.

My role in this process will be that of a group facilitator supporting discussion, giving direction, and encouraging opinions and suggestions. In addition, I will be responsible for recording the information produced from the Focus Group process and ensuring that the session does not exceed the recommended time limit of two hours.

Approximately five to seven days prior to your Focus Group's meeting date, you will receive a pre-information packet containing materials related to the following topics and issues:

A. Critical facts about HIV/AIDS
B. Key definitions
C. Statistical data regarding HIV/AIDS affecting Native Americans
D. Suggestions concerning HIV prevention e.g. universal precautions
E. Articles pertaining to:

1. HIV/AIDS-Legal & confidentiality issues
2. HIV/AIDS-Affecting minorities
3. HIV/AIDS-Foster Care
4. HIV/AIDS-Michigan Department of Social Services policy statement

Please review this information carefully. Hopefully, the pre-information packet will assist you in your preparation and participation in the Focus Group discussions. I would suggest that you bring this packet with you when your group meets to be used as a reference aid.

Finally, with this letter I am sending you a questionnaire. You will find instructions at the top of the three-page questionnaire. Please read the directions carefully. Read each statement, then promptly circle the number which best reflects your personal level of agreement or disagreement. Do not ponder the statements at length. Your impulsive, first-reaction responses will be the answers most valuable to us. Remember, this is not a test and therefore there are no right or wrong answers. You have a right to whatever level of agreement or disagreement you might circle. When completed, return the questionnaire to your assigned contact person. The purpose of this exercise is to allow me to measure as to whether or not the Focus Group process attained Goal II - enhancing your knowledge and attitude regarding HIV/AIDS issues and the need for appropriate policy.

I look forward to meeting and working with you on this important task. It is my hope that you will find this process both informative and enjoyable. Again, many thanks for your time and participation.

Sincerely yours,

D. Pete Holzemer
Casework Supervisor

DPH/laj

APPENDIX D

REFERENCE GROUP LETTER OF INTRODUCTION/QUESTIONNAIRE

February 21, 1993

Dear Participant:

It is a pleasure to count you among the individuals who have agreed to participate in a process to which will provide suggestions and recommendations for an HIV/AIDS policy which we hope will become an integral part of the Michigan Indian Child Welfare Agency.

You will find instructions at the top of the three-page questionnaire. Please read these directions carefully. Read each statement, then promptly circle the number which best reflects your personal level of agreement or disagreement. Do not ponder the statements at length. Your impulsive, first-reaction responses will be the answers most valuable to us. Remember, this is not a test and therefore there are no right or wrong answers. You have a right to whatever level of agreement or disagreement you might circle.

Please complete the attached questionnaire and return it to your contact person. Again, my special thanks to you for your valuable help in this important task.

Sincerely yours,

D. Pete Holzemer
Case Work Supervisor

DPH/laj

QUESTIONNAIRE

INSTRUCTIONS: After each statement circle the number which best reflects your personal opinion, using the following definitions:

5 = I VERY MUCH AGREE with this statement.
4 = I am inclined to AGREE with this statement.
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1.	If an employee is HIV infected, the individual should be prohibited from using restrooms available to other employees.	5	4	3	2	1
2.	When caring for an HIV positive person where one is apt to come into contact with any body secretions, the care-giver should wear rubber (latex) gloves.	5	4	3	2	1
3.	HIV infected individuals or AIDS patients should be isolated from others without the virus or disease.	5	4	3	2	1
4.	If a new mother who is HIV infected does not breast-feed her infant, her infection cannot be transmitted to the child.	5	4	3	2	1
5.	Seeking better treatment of a cure for AIDS should be a national priority.	5	4	3	2	1
6.	HIV infection and AIDS are probably God's way of punishing individuals for immoral behavior.	5	4	3	2	1
7.	Persons infected with HIV must be presumed to be infectious even if they show no symptoms of AIDS.	5	4	3	2	1
8.	If an HIV-infected person ceases all high risk activity, such as unsafe sex and shared needle use, the person will not develop AIDS.	5	4	3	2	1
9.	If one has not been actively involved in homosexual activity, that person need not worry about being HIV positive.	5	4	3	2	1
10.	A child should never be placed in an adoptive or foster home where a resident is known to be HIV infected or have AIDS.	5	4	3	2	1
11.	Wiping a shared needle with a clean facial tissue will remove the risk of HIV infection.	5	4	3	2	1
12.	HIV infected persons and AIDS patients deserve to be treated with compassion and the best available health care.	5	4	3	2	1
13.	With all auto-immune diseases there is a risk of developing AIDS.	5	4	3	2	1

14.	One's sex life is his or her own business and of no concern to his or her sex partner.	5	4	3	2	1
15.	An HIV infected child must never be allowed to share a bedroom with a non-efected child.	5	4	3	2	1
16.	Any person who is HIV infected or has AIDS can be assumed to have been involved in a deviate or otherwise socially or morally unacceptable life style.	5	4	3	2	1
17.	An HIV-infected child should never be placed in an adoptive or foster home.	5	4	3	2	1
18.	If one has come into contact with HIV and after 30 days does not test HIV positive, this person never will.	5	4	3	2	1
19.	AIDS is a male disease and therefore females need not worry about it.	5	4	3	2	1
20.	A person who is HIV-infected must refrain from all sexual activity with others.	5	4	3	2	1
21.	Wheelchair-bound, frail individuals, especially younger adults, are most likely victims of HIV infection or AIDS.	5	4	3	2	1
22.	HIV infection and AIDS are just one more indication of the decay of family values.	5	4	3	2	1
23.	More often than not HIV infected persons or AIDS patients are "weirdos" to be avoided.	5	4	3	2	1
24.	One should never hug or embrace a person known to be HIV positive.	5	4	3	2	1
25.	Some nationalities and races are more likely by nature to be immune to HIV and AIDS.	5	4	3	2	1
26.	One should be fearful of handling the soiled clothing of HIV-infected individuals because doing so is likely to result in contacting the virus.	5	4	3	2	1
27.	A major source of HIV is a toilet seat in a public restroom.	5	4	3	2	1
28.	It is important that a company or agency do all that is possible to refrain from hiring anyone who is HIV infected.	5	4	3	2	1
29.	Physical contact with another's HIV-infected blood can transmit the virus to another.	5	4	3	2	1
30.	Gay men and lesbians, prone to HIV infection and AIDS, do not deserve the same level of medical attention as "straight" persons.	5	4	3	2	1

31.	Wearing a condom during sex will assure a male that he will not become HIV infected.	5	4	3	2	1
32.	Because or the HIV risk, one should refuse blood transfusions, regardless of the medical source.	5	4	3	2	1
33.	Persons who are HIV infected or have AIDS have only themselves to blame.	5	4	3	2	1
34.	Because of the HIV risk, people should be discouraged from donating blood.	5	4	3	2	1
35.	Anyone who is HIV positive can be certain of having AIDS sooner or later.	5	4	3	2	1
36.	If a staff member is found to be HIV infected, the employee should be promptly dismissed.	5	4	3	2	1
37.	HIV infection and AIDS are the result of homosexual activity and therefore should not be a high medical priority.	5	4	3	2	1
38.	Hospitals should be free to refuse treating HIV symptoms and AIDS to protect other patients.	5	4	3	2	1
39.	So long as an HIV-infected person takes safety precautions, he or she need not assume any responsibility to inform a sexual partner of his or her infection.	5	4	3	2	1
40.	Our society should do all possible to engage the active participation and inclusion of HIV infected persons, taking only those precautions which are necessary and appropriate.	5	4	3	2	1

APPENDIX E

PROPOSED FOCUS GROUP PROCESS

APPENDIX E

PROPOSED FOCUS GROUP PROCESS

Allotted Time: 2 hours
Facilitator: D. Pete Holzemer

Material Needs:

1. Name Tags for all participants.
2. Newsprint and Easel
3. Wide Felt Tip Pens (Water base, not toxic)
4. Masking Tape
5. Scrap Paper and Pencils for all participants.
6. Tape Recorder

Introductory Presentation: (15 minutes)

1. Brief introduction of Facilitator and self introduction of all participants (name, tribe -if appropriate --, from (location) and title or role.

2. Briefly explain role of facilitator:
   a. To assist participants to accomplish a task in a shorter time than could be realized if doing the process alone, and to record on newsprint the responses and results, NOT to control input content.
   b. Review the pre-distributed materials in a brief broad-brush manner. Explain that material is meant to enhance and/or broaden their knowledge of HIV, not to determine or control their responses during the process.
   c. Explain the purpose of the process; to seek their input and recommendation regarding an HIV policy for the agency. Review the total practicum process, including the fact that their input and recommendations will be studied and evaluated by a select group of professionals (e.g.: legal, medical experts, etc.) Offer a commitment that their input and recommendations will be honored to the greatest <u>possible</u> extent.
   d. Ask that if what you (or your recorder) writes on newsprint does not adequately reflect what was said, that a proper revision should be called for immediately for.
   e. Briefly outline the major steps of the process which you will employ, pointing out that you will explain each process step before beginning it. Promise that the process will be concluded in no more than two hours.

THE PROCESS AND ITS STEPS:

Concerns: (30 minutes)

Explain that you understand any effort to develop a policy or policies related to HIV will result in concerns for those who it will or might effect, and that you need to better know these concerns in order to take them into account in further policy development. Point out that concerns are assumptional. As assumptions they are defined as those things which may or may not be factually true, but are nonetheless held as true by the individual sharing them during this step of the process. Therefore NO ONE MAY ARGUE WITH OR DEBATE ANOTHER'S EXPRESSED ASSUMPTION. It will be recorded on newsprint as it is offered. Brief questions of clarification, however, are permitted, if necessary. Concerns should be expressed without statements of rationale. Brief rationales may be needed if clarification is called for. Should another person wish to add to or otherwise revise a recorded concern, this is only permissible with the expressed approval of the originator of the concern. Should another participant strongly disagree with an expressed concern, he or she is free to offer an opposing expression of concern which will be recorded in the same fashion.

When recording expressed concerns on newsprint, letter them alphabetically ("A", "B", etc.) Numbering them will too easily imply priorities which are not intended. If the number of concerns exceeds 26, begin again with double letters ("AA", etc.). As each newsprint sheet is filled, remove it from the easel and tape it to a wall where all can view it.

EXAMPLE:

Concerns:
A. That anyone known to be other than sexually "straight" will be treated with less respect and concern.
B. That all HIV cases will be assumed to have been sexually transmitted.

The group will likely be slow in beginning to express concerns. The Facilitator must be patient, continuing to explain the process task, but DO NOT offer any specific examples. To do so will skew the input. Concerns will be expressed, one statement leading to another. Usually a lull will occur after a period of time. The Facilitator should not assume that the participants have exhausted their expression of concerns. The Facilitator should ask the participants to think about additional necessary expressions of concern as he reads aloud what has already been recorded on newsprint. Often the offerings which follow this reading will be far more important and to the point than those expressed earlier. When this phase is completed, be sure that no one has any further concerns to offer before closing this phase of the process.

Consolidation or Combining of Concerns: (10 minutes)

Ask the participants to review the listing of concerns, looking for any concerns which say essentially the same thing. Ask the participants for suggestions of concerns which can be combined because of basic duplication of expression. This should be a very brief phase of the process. If, for example, a participant suggests that Concern C and Concern F are basically the same and should be combined, the facilitator should ask if any other participant disagrees with this suggestion combination. If only one participant disagrees, the suggestion to combine should NOT be made. Total consensus must be insisted upon in order to combine Concern C with Concern F, resulting in Concern CF. The facilitator should point out that combinations should be minimal to prevent ending up with a "glob" of combined verbiage with little meaning and functional use.

Break and Individual Review of Concerns: (15 minutes)

Call for a break during which each participant should review the concerns on newsprint (noting those which are combined, e.g.: "CF) and jot down on paper the letters (not full statements) of UP TO FIVE concerns which the individual participant thinks or feels is SHOULD BE CONSIDERED WITH THE MOST IMPORTANCE IN DEVELOPING AN HIV POLICY OR POLICIES. "Five" is an arbitrary number. If the list of concerns is short, a lower number may be more appropriate.

Ranking: (10 minutes)

When the group has reconvened, the facilitator should ask for a show of hands to determine the group's ranking of importance from among the list of concerns. Begin with the first concern by asking, "How many of you listed Concern A among your up to five most important concerns?" Count raised hands and write this number on the newsprint next to the concern. Use a different color felt pen (e.g.: red). Continue through the entire list. When this is completed, review with the participants the results, pointing out the most important concern held corporately by the group, and continue in descending order.

Need Statements: (25 minutes)

With the concerns still posted on the wall, explain and begin the final phase of the process. Point out that on the basis of the expressed concerns and the ranking with the group has assigned to them, you are asking the participants to share Statements of Need which in their individual judgements should be reflected in any agency HIV policy or policies. List these on newsprint in the same manner in which concerns were listed. Explain that you are asking them to respond to a completion of the following statement: THEREFORE, ON THE BASIS OF OUR RANKED CONCERNS, THERE IS A NEED THAT AN AGENCY HIV POLICY INCLUDE...

EXAMPLE:

Need Statements
A. A commitment to a non-judgemental, professional approach to anyone with the HIV virus.
B. An assurance that the Native American culture will be respected.

Ranking: (10 minutes)

As with concerns, ask each participant to select UP TO FIVE (less, if appropriate) NEED STATEMENTS WHICH SHOULD BE INCLUDED WITHIN ANY AGENCY HIV POLICY WITH THE GREATEST IMPORTANCE. Use a show of hands to determine an informal ranking of importance.

Conclusion: (5 minutes)

Point out that other Focus Groups will participate in the same process. Thank them for their participation and assure them that their input will be seriously CONSIDERED (as opposed to "followed"). Promise them that they will receive a verbatim readout report of the newsprint within a reasonable length of

APPENDIX F

HELPFUL SUGGESTIONS FOR FOCUS GROUP MODERATORS

APPENDIX F

HELPFUL SUGGESTIONS FOR FOCUS GROUP MODERATORS

Donald L. Wilhelm

1. Introduce yourself to the Focus Group participants. Be sure that all present understand your role within the agency, but also understand your role at this session as a moderator/facilitator present to solicit and record their input and recommendations. Explain that you have attempted to come with no pre-conceived assumptions of their responses during the session and will honor whatever recommendations are shared.

2. If there is any doubt that the participants do not already know each other well, take time to allow each person to introduce him or herself to the group. These introductions should be brief, including one's name, where they are from, and an identification of any position title they might hold within or related to the agency (e.g.: foster parent, etc.)

3. Explain that the process for the meeting is called a Focus Group process. That is, a collective group interview to ascertain their recommendations. Present a brief, broad-brush explanation of the planned process and its steps with an assurance that further details will be explained as as each process step is introduced. Help the participants understand that they are NOT making decisions, but rather offering recommendations which will be seriously considered.

4. Do not allow one or two persons to monopolize the discussion. Insist that comments be brief and to the point. Explain that long rationales are not necessary and only steal time from others who also need to participate.

5. Keep in mind that participants with more introverted personalities will be less likely to speak up. Therefore it will be important to draw them out -- perhaps with direct requests for their observations and recommendations. Just because one is a vocal extrovert does not cause their opinions to be more valuable and/or valid.

6. Watch for non-verbals. Facial expressions and body language often say more than words. Introverted participants will be most likely to "speak" silently through non-verbals. Use these non-verbals as an invitation to draw forth expressed opinions. Because of the importance of non-verbals it is helpful to have participants seated in a circle and not encumbered by a table which will hide important non-verbal messages.

7. Finally, watch your own verbal and non-verbal reactions to what is said. You are there to receive input and recommendations, not to make judgments about anything which is said. Do not allow yourself to inadvertently judge. Affirm and encourage participation, but do not judge content.

APPENDIX G

FOCUS GROUP ANALYSIS AND OBSERVATIONS

APPENDIX G

FOCUS GROUP ANALYSIS AND OBSERVATIONS

Donald L. Wilhelm

INSTRUCTIONS: So soon as possible after the completion of each Focus Group session -- not longer than 24 hours -- the facilitator should prepare a brief report in journal nature which includes the following possible information and any additional data judged to be important and pertinent.

FOCUS GROUP #_____ LOCATION: _____

DATE: _____ TIME: from _____ to _____

1. Number of Focus Group participants. Number who were male and number who were female. An approximation of participants' ages according to sex (e.g.: Younger than 20, 20-35. 35-50, 50-65. older than 65.)

2. How well did the participants appear to know each other in advance of the session? To what extent did they appear to not to know each other? Was there any noticeable split between some who knew each other well and others who were new and unfamiliar with others in the group?

3. How do you evaluate the friendliness and cohesiveness of the group? Did they work well together? Did they appear to respect each other's comments and opinions. Were there specific participants who did not appear to be so well included in the group? If so, why do you think this was?

4. Did any obvious, perhaps strong, polarities of opinion occur during the Focus Group session? If so, describe how this diversity seemed to numerically split out among the participants (e.g.: one or two individuals against the others, rather evenly split, etc.). Can you identify any possible or obvious factors which contributed to this polarity (sex, age, social status, professional status, etc.)? How well do you feel this polarity was handled at the session?

5. How well did the individuals participate in the session? Did everyone participate and contribute? If not, what do you think caused some individuals to hesitate becoming involved (shyness, hostility, etc.) What did you do to draw this or these persons out?

6. How well did the planned Focus Group process work? Was it necessary to make any process revisions or adjustments during the session? Why were these changes needed or called for?

7. In your judgement, how do you think the participants felt

about their involvement in the Focus Group? To what extent do you feel comfortable making a general judgement? Or do you find that there probably was a diversity of feelings? Describe this diversity?

8. How do you feel about your role as Focus Group facilitator? What were your strengths, weaknesses? What did you learn as a result of facilitating this Focus Group session?

9. As a result of this Focus Group session, what would you consider changing at the next session and why?

APPENDIX H

PRE/POST QUESTIONNAIRE RESULTS

SURVEY RESULTS

KNOWLEDGE:

1. When caring for an HIV positive person where one is apt to come into contact with any body secretions, the care-giver should wear rubber (latex) gloves.

	AGREE	DISAGREE	DON'T KNOW
Focus Group A			
Pre	100.0%	0%	0%
Post	100.0%	0%	0%
Focus Group B			
Pre	100.0%	0%	0%
Post	100.0%	0%	0%
Focus Group C			
Pre	100.0%	0%	0%
Post	100.0%	0%	0%
Focus Group D			
Pre	100.0%	0%	0%
Post	80.0% ↓	0%	20.0%
All Focus Groups			
Pre	100.0%	0%	0%
Post	96.4% ↓	0%	03.6%
Reference Group			
Pre	91.2%	02.9%	05.9%

2. If a new mother who is HIV infected does not breast-feed her infant, her infection cannot be transmitted to the child.

Focus Group A			
Pre	0%	85.7%	14.3%
Post	16.7%	66.6% ↓	16.7%
Focus Group B			
Pre	14.3%	85.7%	0%
Post	14.2%	42.9% ↓	42.9%
Focus Group C			
Pre	07.1%	78.0%	14.9%
Post	50.0%	40.0% ↓	10.0%
Focus Group D			
Pre	14.3%	28.6%	57.1%
Post	0%	0% ↓	100.0%
All Focus Groups			
Pre	08.3%	71.7%	20.0%
Post	25.0%	39.3% ↓	35.7%
Reference Group			
Pre	14.7%	47.1%	38.2%

3. Persons infected with HIV must be presumed to be infectious even if they show no symptoms of AIDS.

Focus Group A			
Pre	71.4%	0%	28.6%
Post	100.0%	0%	0%
Focus Group B			
Pre	57.1%	14.3%	28.6%
Post	42.8%	28.6%	28.6%
Focus Group C			
Pre	07.1%	28.6%	64.3%
Post	70.0%	0%	30.0%
Focus Group D			
Pre	57.1%	28.6%	14.3%
Post	40.0%	20.0%	40.0%
All Focus Groups			
Pre	**31.4%**	40.0%	28.6%
Post	**64.3%**	25.0%	10.7%
Reference Group			
Pre	**55.9%**	20.6%	23.5%

4. If an HIV-infected person ceases all high risk activity, such as unsafe sex and shared neddle use. the person will not develop AIDS.

Focus Group A			
Pre	14.3%	85.7%	0%
Post	0%	100.0%	0%
Focus Group B			
Pre	0%	85.7%	14.3%
Post	0&	100.0%	0%
Focus Group C			
Pre	07.1%	85.8%	07.1%
Post	10.0%	90.0%	0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	02.9%	**85.7%**	11.4%
Post	03.6%	**96.4%**	0%
Reference Group			
Pre	02.9%	**82.4%**	14.7%

5. If one has not been actively involved in homosexual activity, that person need not worry about being HIV positive.

Focus Group A			
Pre	14.3%	85.7%	0%
Post	0%	83.3%	16.7%
Focus Group B			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group C			
Pre	0%	92.9%	07.1%
Post	10.0%	90.0%	0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	80.0%	20.0%
All Focus Groups			
Pre	02.9%	**94.2%**	02.9%
Post	03.6%	**89.3%**	07.1%
Reference Group			
Pre	02.9%	**91.2%**	05.9%

6. Wiping a shared neddle with a clean facial tissue will remove the risk of HIV infection.

Focus Group A			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group B			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group C			
Pre	0%	100.0%	
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	0%	**100.0%**	0%
Post	0%	**100.0%**	0%
Reference Group			
Pre	0%	**94.1%**	05.9%

7. With all auto-immune diseases there is a risk of developing AIDS.

Focus Group A			
Pre	28.6%	14.3%	57.1%
Post	66.7%	33.3%	0%
Focus Group B			
Pre	28.6%	57.1%	14.3%
Post	57.1%	14.3%	28.6%
Focus Group C			
Pre	21.4%	42.9%	35.7%
Post	30.0%	50.0%	20.0%
Focus Group D			
Pre	14.3%	28.6%	57.1%
Post	20.0%	40.0%	40.0%
All Focus Groups			
Pre	22.9%	**37.1%**	40.0%
Post	42.9%	**25.0%**	32.1%
Reference Group			
Pre	23.5%	**14.7%**	61.8%

8. If one has come into contact with HIV and after 30 days does not test HIV positive, this person never will.

Focus Group A			
Pre	0%	85.7%	14.3%
Post	0%	66.7%	33.3%
Focus Group B			
Pre	0%	85.7%	14.3%
Post	0%	100.0%	0%
Focus Group C			
Pre	0%	85.7%	14.3%
Post	0%	80.0%	20.0%
Focus Group D			
Pre	0%	57.1%	42.9%
Post	0%	100.0%	0%
All Focus Groups			
Pre	0%	**80.0%**	20.0%
Post	0%	**85.7%**	14.3%
Reference Group			
Pre	05.9%	**85.3%**	08.8%

9. AIDS is a male disease and therefore females need not worry about it.

Focus Group A			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group B			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group C			
Pre	0%	92.9%	07.1%
Post	10.0%	90.0%	0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	0%	**97.1%**	02.9%
Post	03.6%	**96.4%**	0%
Reference Group			
Pre	05.9%	**94.1%**	0%

10. A person who is HIV-infected must refrain from all sexual activity with others.

Focus Group A			
Pre	28.6%	14.3%	57.1%
Post	33.4%	66.6%	0%
Focus Group B			
Pre	28.6%	57.1%	14.3%
Post	42.8%	28.6%	28.6%
Focus Group C			
Pre	35.7%	21.5%	42.8%
Post	40.0%	50.0%	10.0%
Focus Group D			
Pre	14.3%	57.1%	28.6%
Post	20.0%	60.0%	20.0%
All Focus Groups			
Pre	28.6%	**34.3%**	37.1%
Post	35.7%	**50.0%**	14.3%
Reference Group			
Pre	44.1%	**35.3%**	20.6%

11. One should never hug or embrace a person known to be HIV positive.

Focus Group A			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group B			
Pre	0%	100.0%	0%
Post	14.3%	85.7%	0%
Focus Group C			
Pre	07.1%	85.8%	07.1%
Post	0%	100.0%	0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	02.9%	**94.2%**	02.9%
Post	03.6%	**96.4%**	0%
Reference Group			
Pre	0%	**97.1%**	02.9%

12. Some nationalities and races are more likely by nature to be immune to HIV and AIDS.

Focus Group A			
Pre	0%	85.7%	14.3%
Post	0%	33.3%	66.7%
Focus Group B			
Pre	14.3%	85.7%	0%
Post	14.3%	85.7%	0%
Focus Group C			
Pre	0%	85.7%	14.3%
Post	0%	60.0%	40.0%
Focus Group D			
Pre	0%	85.7%	14.3%
Post	0%	60.0%	40.0%
All Focus Groups			
Pre	02.8%	**88.5%**	08.7%
Post	03.6%	**67.8%**	28.6%
Reference Group			
Pre	17.6%	**67.7%**	14.7%

13. One should be fearful of handling the soiled clothing of HIV-infected individuals because doing so is likely to result in contacting the virus.

Focus Group A			
Pre	14.2%	42.9%	42.9%
Post	33.3%	33.3%	33.4%
Focus Group B			
Pre	28.6%	42.8%	28.6%
Post	85.7%	0%	14.3%
Focus Group C			
Pre	07.1%	71.5%	21.4%
Post	20.0%	50.0%	30.0%
Focus Group D			
Pre	14.3%	57.1%	28.6%
Post	20.0%	60.0%	20.0%
All Focus Groups			
Pre	11.4%	**62.9%**	25.7%
Post	39.3%	**35.7%**	25.0%
Reference Group			
Pre	14.7%	**47.1%**	38.2%

14. A major source of HIV is a toilet seat in a public restroom.

Focus Group A			
Pre	0%	85.7%	14.3%
Post	0%	100.0%	0%
Focus Group B			
Pre	14.3%	71.4%	14.3%
Post	14.3%	71.4%	14.3%
Focus Group C			
Pre	07.1%	92.9%	0%
Post	10.0%	70.0%	20.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	08.7%	**80.0%**	11.3%
Post	07.1%	**82.2%**	10.7%
Reference Group			
Pre	05.9%	**67.6%**	26.5%

15. Physical contact with another's HIV-infected blood can transmit the virus to another.

Focus Group A			
Pre	85.7%	14.3%	0%
Post	83.3%	0%	16.7%
Focus Group B			
Pre	85.7%	14.3%	0%
Post	100.0%	0%	0%
Focus Group C			
Pre	78.6%	07.1%	14.3%
Post	80.0%	20.0%	0%
Focus Froup D			
Pre	57.1%	0%	42.9%
Post	80.0%	0%	20.0%
All Focus Groups			
Pre	**77.1%**	08.7%	14.2%
Post	**85.7%**	10.7%	03.6%
Reference Group			
Pre	**76.4%**	11.8%	11.8%

16. Wearing a condom during sex will assure a male that he will not become HIV infected.

Focus Group A			
Pre	57.1%	42.9%	0%
Post	0%	83.3%	16.7%
Focus Group B			
Pre	14.3%	85.7%	0%
Post	42.8%	57.2%	0%
Focus Group C			
Pre	28.6%	50.0%	21.4%
Post	30.0%	70.0%	0%
Focus Group D			
Pre	0%	85.7%	14.3%
Post	0%	100.0%	0%
All Focus Groups			
Pre	25.7%	**62.9%**	11.4%
Post	21.4%	**75.0%**	03.6%
Reference Group			
Pre	20.6%	**70.6%**	08.8%

17. Because of the HIV risk, one should refuse blood transfusions, regardless of the medical source.

Focus Group A			
Pre	14.3%	71.4%	14.3%
Post	50.0%	16.7%	33.3%
Focus Group B			
Pre	0%	100.0%	0%
Post	0%	71.4%	28.6%
Focus Group C			
Pre	07.1%	85.8%	7.1%
Post	30.0%	50.0%	20.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	05.7%	**88.6%**	05.7%
Post	21.4%	**57.2%**	21.4%
Reference Group			
Pre	05.9%	**85.3%**	08.8%

18. Because of the HIV risk, people should be discouraged from donating blood.

Focus Group A			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group B			
Pre	14.3%	85.7%	0%
Post	28.6%	57.1%	14.3%
Focus Group C			
Pre	14.3%	85.7%	0%
Post	10.0%	70.0%	20.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	05.7%	**94.3%**	0%
Post	10.7%	**78.6%**	10.7%
Reference Group			
Pre	08.8%	**91.2%**	0%

19. Anyone who is HIV positive can be certain of having AIDS sooner or later.

Focus Group A			
Pre	42.8%	28.6%	28.6%
Post	33.3%	50.0%	16.7%
Focus Group B			
Pre	28.6%	28.6%	42.8%
Post	57.1%	42.9%	0%
Focus Group C			
Pre	07.1%	35.8%	57.1%
Post	50.0%	30.0%	20.0%
Focus Group D			
Pre	0%	71.4%	28.6%
Post	20.0%	80.0%	0%
All Focus Groups			
Pre	17.1%	**40.0%**	42.9%
Post	42.9%	**46.4%**	10.7%
Reference Group			
Pre	50.0%	**26.5%**	23.5%

20. So long as an HIV-infected person takes safety precautions, he or she need not assume any responsibility to inform a sexual partner of his or her infection.

Focus Group A			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group B			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group C			
Pre	07.1%	92.9%	0%
Post	50.0%	20.0%	30.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	80.0%	20.0%
All Focus Groups			
Pre	02.9%	**97.1%**	0%
Post	0%	**92.9%**	07.1%
Reference Group			
Pre	70.6%	**08.8%**	20.6%

WOW!

ATTITUDE

1. If an employee is HIV-infected, the individual should be prohibited from using restrooms available to other employees.

Focus Group A			
Pre	0%	100.0%	0%
Post	16.7%	83.3%	0%
Focus Group B			
Pre	14.3%	85.7%	0%
Post	14.3%	85.7%	0%
Focus Group C			
Pre	0%	78.5%	21.5%
Post	20.0%	60.0%	20.0%
Focus Group D			
Pre	0%	85.7%	14.3%
Post	0%	100.0%	0%
All Focus Groups			
Pre	02.9%	**85.7%**	11.4%
Post	14.3%	**78.6%**	07.1%
Reference Group			
Pre	11.8%	**55.8%**	32.4%

2. HIV-infected individuals or AIDS patients should be isolated from others without the virus or disease.

Focus Group A			
Pre	0%	85.7%	14.3%
Post	16.7%	66.6%	16.7%
Focus Group B			
Pre	28.6%	71.4%	0%
Post	14.3%	57.1%	28.6%
Focus Group C			
Pre	07.1%	71.4%	21.5%
Post	10.0%	90.0%	0%
Focus Group D			
Pre	0%	85.7%	14.3%
Post	80.0%	0%	20.0%
All Focus Groups			
Pre	28.6%	**60.0%**	11.4%
Post	35.7%	**60.7%**	03.6%
Reference Group			
Pre	20.6%	**55.8%**	23.6%

3. Seeking better treatment of a cure for AIDS should be a national priority.

Focus Group A			
Pre	100.0%	0%	0%
Post	100.0%	0%	0%
Focus Group B			
Pre	71.4%	28.6%	0%
Post	100.0%	0%	0%
Focus Group C			
Pre	86.7%	0%	14.3%
Post	90.0%	10.0%	0%
Focus Group D			
Pre	100.0%	0%	0%
Post	95.7%	04.3%	0%
All Focus Groups			
Pre	**85.8%**	07.1%	07.1%
Post	**95.7%**	04.3%	0%
Reference Group			
Pre	**91.2%**	05.9%	02.9%

4. HIV infection and AIDS are probably God's way of punishing individuals for immoral behavior.

Focus Group A			
Pre	14.3%	85.7%	0%
Post	0%	83.3%	16.7%
Focus Group B			
Pre	0%	57.2%	42.8%
Post	28.6%	57.1%	14.3%
Focus Group C			
Pre	85.7%	0%	14.3%
Post	0%	90.0%	10.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	37.2%	**31.4%**	31.4%
Post	07.1%	**82.2%**	10.7%
Reference Group			
Pre	08.8%	**67.7%**	23.5%

5. A child should never be placed in an adoptive or foster home where a resident is known to be HIV positive.

Focus Group A			
Pre	14.3%	28.6%	57.1%
Post	16.7%	50.0%	33.3%
Focus Group B			
Pre	28.6%	71.4%	0%
Post	28.6%	28.6%	42.8%
Focus Group C			
Pre	21.4%	35.7%	42.9%
Post	30.0%	50.0%	20.0%
Focus Group D			
Pre	0%	85.7%	14.3%
Post	0%	100.0%	0%
All Focus Groups			
Pre	17.1%	**37.1%**	45.8%
Post	21.4%	**53.6%**	25.0%
Reference Group			
Pre	23.5%	**53.0%**	23.5%

6. HIV-infected persons and AIDS patients deserve to be treated with compassion and the best available health care.

Focus Group A			
Pre	100.0%	0%	0%
Post	66.7%	33.3%	0%
Focus Group B			
Pre	100.0%	0%	0%
Post	57.1%	14.3%	28.6%
Focus Group C			
Pre	100.0%	0%	0%
Post	100.0%	0%	0%
Focus Group D			
Pre	100.0%	0%	0%
Post	80.0%	20.0%	o%
All Focus Groups			
Pre	**100.0%**	0%	0%
Post	**96.4%**	03.6%	0%
Reference Group			
Pre	**02.9%**	91.2%	05.9%

wow!

7. One's sex life is his or her own business and of no concern to his or her sex partner.

Focus Group A			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group B			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group C			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group D			
Pre	0%	100.0%	0%
Post	20.0%	80.0% ↓	0%
All Focus Groups			
Pre	0%	**100.0%**	0%
Post	03.6%	**96.4%** ↓	0%
Reference Group			
Pre	02.9%	**94.2%**	02.9%

8. An HIV-infected child must never be allowed to share a bedroom with a non-infected child.

Focus Group A			
Pre	0%	71.4% ↑	28.6%
Post	0%	83.3%	16.7%
Focus Group B			
Pre	28.6%	71.4%	0%
Post	42.8%	42.8% ↓	14.4%
Focus Group C			
Pre	14.3	57.1% ↑	28.6%
Post	20.0%	60.0%	20.0%
Focus Group D			
Pre	0%	85.7% ↑	14.3%
Post	0%	100.0%	0%
All Focus Groups			
Pre	11.4%	**71.5%**	17.1%
Post	17.9%	**67.9%** ↓	14.2%
Reference Group			
Pre	17.6%	**64.8%**	17.6%

9. Any person who is HIV-infected or has AIDS can be assumed to have been involved in a deviate or otherwise socially or morally unacceptable life style.

Focus Group A			
Pre	03.6%	96.4%	0%
Post	33.3%	66.7%	0%
Focus Group B			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group C			
Pre	07.1%	92.9%	0%
Post	0%	90.0%	10.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	02.9%	**97.1%**	0%
Post	07.1%	**89.3%**	03.6%
Reference Group			
Pre	05.9%	**85.3%**	08.8%

10. An HIV-infected child should never be placed in an adoptive or foster home.

Focus Group A			
Pre	03.6%	82.1%	14.3%
Post	0%	66.7%	33.3%
Focus Group B			
Pre	14.3%	71.4%	14.3%
Post	0%	85.7%	14.3%
Focus Group C			
Pre	0%	85.8%	14.2%
Post	10.0%	70.0%	20.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	02.9%	**85.7%**	11.4%
Post	03.6%	**78.6%**	17.8%
Reference Group			
Pre	05.9%	**85.3%**	08.8%

11. Wheelchair-bound, frail individuals, especially younger adults, are most likely victims of HIV infection or AIDS.

Focus Group A			
Pre	0%	96.4%	03.6%
Post	0%	100.0%	0%
Focus Group B			
Pre	0%	85.7%	14.3%
Post	0%	100.0%	0%
Focus Group C			
Pre	0%	100.0%	0%
Post	10.0%	80.0%	10.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	0%	97.1%	02.9%
Post	03.6%	92.8%	03.6%
Reference Group			
Pre	44.2%	35.4%	20.4%

Wow!

12. HIV infection and AIDS are just one more indication of the decay of family values.

Focus Group A			
Pre	11.8%	73.5%	14.7%
Post	33.4%	66.6%	0%
Focus Group B			
Pre	14.3%	71.4%	14.3%
Post	28.6%	57.1%	14.3%
Focus Group C			
Pre	21.5%	78.5%	0%
Post	20.0%	70.0%	10.0%
Focus Group D			
Pre	0%	85.7%	14.3%
Post	0%	100.0%	0%
All Focus Groups			
Pre	14.2%	77.1%	08.7%
Post	25.0%	67.9%	07.1%
Reference Group			
Pre	0%	91.2%	08.8%

13. More often than not HIV-infected persons or AIDS patients are "weirdos" to be avoided.

Focus Group A			
Pre	03.6%	92.8%	03.6%
Post	0%	100.0%	0%
Focus Group B			
Pre	0%	85.7%	14.3%
Post	0%	100.0%	0%
Focus Group C			
Pre	07.1%	92.9%	0%
Post	0%	80.0%	20.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	20.0%	80.0%	0%
All Focus Groups			
Pre	02.9%	**91.4%**	05.7%
Post	03.6%	**89.3%**	07.1%
Reference Group			
Pre	05.8%	**94.2%**	0%

14. It is important that a company or agency do all that is possible to refrain from hiring anyone who is HIV-infected.

Focus Group A			
Pre	03.6%	85.7%	10.7%
Post	0%	83.3%	16.7%
Focus Group B			
Pre	0%	85.7%	14.3%
Post	0%	100.0%	0%
Focus Group C			
Pre	07.1%	85.8%	07.1%
Post	0%	80.0%	20.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	02.8%	**88.5%**	08.7%
Post	0%	**87.0%**	13.0%
Reference Group			
Pre	05.9%	**76.5%**	17.6%

15. Gay men and lesbians, prone to HIV infection and AIDS, do not deserve the same level of medical attention as "straight" persons.

Focus Group A			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group B			
Pre	28.6%	71.4%	0%
Post	14.3%	71.4%	14.3%
Focus Group C			
Pre	0%	100.0%	0%
Post	0%	90.0%	10.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	14.9%	**82.2%**	02.9%
Post	10.7%	**75.0%**	14.3%
Reference Group			
Pre	05.9%	**91.2%**	02.9%

16. Persons who are HIV-infected or have AIDS have only themselves to blame.

Focus Group A			
Pre	14.3%	85.7%	0%
Post	0%	100.0%	0%
Focus Group B			
Pre	14.3%	57.2%	28.5%
Post	14.3%	71.4%	14.3%
Focus Group C			
Pre	07.1%	92.9%	0%
Post	0%	90.0%	10.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	08.6%	**82.8%**	08.6%
Post	03.6%	**89.3%**	07.1%
Reference Group			
Pre	14.7%	**82.4%**	02.9%

17. If a staff member is found to be HIV-infected, the employee should be promptly dismissed.

Focus Group A			
Pre	0%	96.4%	03.6%
Post	0%	83.3% ↓	16.7%
Focus Group B			
Pre	0%	85.7%	14.3%
Post	0%	85.7%	14.3%
Focus Group C			
Pre	0%	92.9%	07.1%
Post	10.0%	90.0% ↓	0%
Focus Group D			
Pre	0%	100.0%	0%
Post	20.0%	80.0% ↓	0%
All Focus Groups			
Pre	0%	**88.6%**	11.4%
Post	07.1%	**78.6%** ↓	14.3%
Reference Group			
Pre	11.8%	**82.3%**	05.9%

18. HIV infection and AIDS are the result of homosexual activity and therefore should not be a high medical priority.

Focus Group A			
Pre	0%	96.4% ↑	03.6%
Post	0%	100.0%	0%
Focus Group B			
Pre	0%	85.7% ↑	14.3%
Post	0%	100.0%	0%
Focus Group C			
Pre	0%	100.0%	0%
Post	10.0%	90.0% ↓	0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	0%	**91.4%** ↑	08.6%
Post	03.6%	**96.4%**	0%
Reference Group			
Pre	02.9%	**94.2%**	02.9%

19. Hospitals should be free to refuse treating HIV symptoms and AIDS to protect other patients.

Focus Group A			
Pre	0%	85.7%	14.3%
Post	16.7%	83.3%	0%
Focus Group B			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
Focus Group C			
Pre	0%	85.8%	14.2%
Post	0%	90.0%	10.0%
Focus Group D			
Pre	0%	100.0%	0%
Post	0%	100.0%	0%
All Focus Groups			
Pre	0%	94.3%	05.7%
Post	02.9%	93.5%	03.6%
Reference Group			
Pre	02.9%	97.1%	0%

20. Our society should do all possible to engage the active participation and inclusion of HIV-infected persons, taking only those precautions which are necessary and appropriate.

Focus Group A			
Pre	57.1%	28.6%	14.3%
Post	100.0%	0%	0%
Focus Group B			
Pre	71.4%	14.3%	14.3%
Post	71.4%	14.3%	14.3%
Focus Group C			
Pre	78.6%	14.3%	07.1%
Post	50,0%	20.0%	30.0%
Focus Group D			
Pre	100.0%	0%	0%
Post	100.0%	0%	0%
All Focus Groups			
Pre	77.1%	14.2%	08.7%
Post	75.0%	10.7%	14.3%
Reference Group			
Pre	70.6%	08.8%	20.6%

APPENDIX I

SUMMARY OF TRIBAL HIV-1 POLICY GUIDELINES

I. SUMMARY OF TRIBAL HIV-1 POLICY GUIDELINES

If adopted, the policies reproduced in this volume should be made available to all community members and employees and serve as the source of Tribal education, employment standards, and community service related to HIV-1.

A. Equal Access to Services

Basic Principle:

No one will be denied services, or offered substandard services, because of real or perceived HIV-1+ antibody status. There is no valid ethical, epidemiological, or legal reason for community programs or businesses to refuse service or employment for an HIV-1+ antibody person who is otherwise qualified for service or employment.

Recommendation:

Tribes adopt a policy statement that explicitly acknowledges full access to services and employment for HIV-1+ persons who are otherwise qualified. In addition, programs should endeavor to educate all community members and program staff about nondiscrimination law as it relates to HIV-1 and AIDS.

B. HIV-1 Education:

Basic Principle:

Education that emphasizes behavioral change is one of the only tools presently available in the fight against transmission of HIV-1. Though difficult, education can be effective in changing knowledge, attitudes, and behaviors.

Recommendation:

Tribal programs and businesses provide education on HIV-1 for all staff, clients, and community members. Education should be integrated into existing program and orientation formats and philosophy and should include, at the least, an explanation of the nature and action of HIV-1, facts about transmission, and personal and occupational risk reduction strategies.

C. Infection Control/Universal Precautions

Basic Principle:

There is a minute risk of HIV-1 exposure through occupational exposure to blood, semen, and vaginal secretions. Despite the fact that it is extremely unlikely that such exposure

would take place in tribal programs and businesses, it is sensible,
for general hygienic reasons and to control infection of other blood-borne diseases; such as Hepatitis B Virus; to adopt simple, accessible infection control procedures and protocols in service settings and business places.

Recommendation:

Tribal programs and businesses adopt an infection control plan appropriate to their setting and service.

D. HIV-1 Antibody Testing

Basic Principle:

The current HIV-1 antibody test has both potential advantages and limitations. The HIV-1 antibody test should not be required as a precondition for employment or services. Persons thinking of getting the test should carefully weigh a number of critical factors before getting the test. Health and social service staff working with clients have a role to play in helping the individual (after appropriate HIV test counselor training) : 1) to decide whether or not to be tested, 2) to learn about resources for testing and their respective advantages and disadvantages, and 3) to provide adequate and appropriate follow-up counseling, or referral for counseling, before and after testing.

Recommendation:

Tribal programs and businesses make clear to all staff and clients their stance on HIV-1 antibody testing. Health and social service staff should help clients reach decisions on the question of being tested, rather than forcing one recommendation over another. Programs and businesses should work to protect client confidentiality in the entire process of test decision-making and actual testing, and should strive to make sure that no client comes to harm because of a positive test result.

E. Confidentiality and HIV-1 Information Management

Basic Principle:

Since a great deal of potential harm can come to people whose HIV-1 positive antibody status is inappropriately or illegally disclosed to third parties, tribal programs and businesses should carefully guard the confidentiality of clients' and staffs' HIV-1 status.

Recommendation:

Tribal programs and businesses should develop and adopt policies that address specific questions about HIV-1 antibody status and confidentiality. The Policies should address issues such as who needs to know when a client self-reports HIV-1 seropositivity, program responsibilities and liabilities in relation to HIV-1 status information, third party disclosure, charting protocols of HIV-1 status, and other matters. Specific recommendations on confidentiality questions are contained in the body of these Guidelines.